

# Quality Care: The Perspectives of Frail Elderly

*Completed in 1996, this narrative was an introductory report to the Partnership Program based on interviews with elderly consumers in Wisconsin. Subjects included individuals enrolled in the Program for All-inclusive Care for the Elderly (PACE) and the Partnership Program at ElderCare of Dane County.*

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## **Introduction**

The thirty-one elderly consumers interviewed for this study consistently evaluated quality of care by the quality of their relationships with providers. In most instances, satisfaction with the interactional component of the relationship was tantamount to satisfaction with the care. Numerous examples of both high and low quality care were consistently defined by the quality of the interactions and the relationship between the consumer and the provider rather than by the clinical outcomes. The relationship with a provider was not and could not be separated out from the quality of either the processes or outcomes of care delivery.

## **Patient Satisfaction Tools**

In general, patient surveys and professional assessments consider competence of the provider, appropriateness of the services, and nature of the outcomes apart from the quality of the personal interactions between patients and their families. These items are evaluated separately most of the time.

Most of the elderly subjects interviewed for this study had never completed a patient satisfaction survey. The few who had done so had clearly based most, if not all, of their responses on their feelings about the primary provider and their relationship with that person. Their responses, regardless of area addressed, were influenced significantly by that primary relationship. Several of the consumers also indicated that they would be unwilling to fill out such a survey, especially if they were unsatisfied with some aspect of the service encounter. This raises serious questions about patient satisfaction surveys that often ask patients to distinguish between the quality of the care and the quality of the interactions. The reluctance to provide

negative feedback, especially when the provider is well liked, would have a skewing effect on patient satisfaction surveys.

## **Methods**

Data collection for the frail elderly population was completed through in-depth, semi structured interviews with frail elderly consumer and their caregivers. Individual, one-on-one interviews were conducted at a setting of the participants choice. Most of these consumers were enrolled through either the PACE or Partnership programs at Eldercare of Dane County. Some interviews were conducted with well elderly for comparison data.

Additional data was collected using participant observation at the PACE and Partnership day center.

Data were collected and analyzed using the Grounded Theory research method. Accordingly, interviews were initially quite open and unstructured, allowing the subjects to establish the topics to be pursued. Subjects were encouraged to talk about health care experiences and how their condition and related services influenced other aspects of their lives. Following each new interview, an analysis was conducted and questions were altered accordingly. The consistency of topics identified by consumers led quickly to a narrowing of the interviewers' focus. Remaining interviews were used to elaborate on these areas, each time also confirming relevance of the topic.

## **RELATIONSHIP WITH PROVIDER**

“And I told that to the doctor, and she was so sympathetic about it, that I couldn’t believe my ears, that she was telling me such kind things and she was so sympathetic that it was just unreal.... And then when she left she had me come

into her office to talk to her, and the tears came to my eyes and I just cried and I told her she's the best doctor in the world." (CONS26A)

Relationships with providers were conceptualized as inextricably related to, indeed the essence of, the services. Quality of care could not be conceptualized apart from the relationship with the provider and the quality of those interactions. Medical outcomes, in most instances, were of secondary importance.

When asked specifically about outcomes, consumers would often describe an interaction with the provider to demonstrate the quality of the relationship rather than address clinical procedures or outcomes. When this consumer was asked to give an example of quality health care, she told the story of how her doctor had come by her home to check on her on Christmas day:

"Well I got sick over Christmas and I couldn't get out of bed...So Christmas day Dr. \_\_\_\_ come out to the house..she left some kind of number she has, that if she's someplace else I could call her, or my daughter could call her...Well, when she came to the house...I was pretty sick... She made you feel like you didn't put her out." (CONS05, 689-763)

In the context of a good relationship with the provider, elderly consumers described several examples of high quality care interactions. These examples demonstrated a high degree of familiarity, between patient and provider, and with provider behaviors that clearly reflected affection toward the patient. In this context, it was rare to find a negative comment about any aspect of the care.

Understanding the centrality of the relationship with the provider, and the implications of this on quality, was pursued throughout interviews with elderly consumers. Frailty can have a powerful, isolating effect. Many of the elderly consumers interviewed had few significant

relationships in their lives. Often they had few living relatives or friends near by. Consequently, having a history with someone (including health care providers) and continuity in a relationship was an important quality of life issue. For many of these frail elderly individuals, their health care provider had known and even cared for their spouses, siblings and friends who were no longer living. Thus, there was a real investment in maintaining relationships with health care providers who were connected to them in ways that went well beyond health care.

### **PROVIDER EXPERTISE**

Expertise, from the elderly consumer's perspective, is the integration of clinical knowledge and intimate personal knowledge. Competent decisions can only be made if all that is unique and special about a particular patient is taken into account. This contrasts with clinicians' understanding of expertise as primarily related to knowing a clinical area which can be brought to bear on the treatment of a patient (someone they may or may not know well).

When expert care is defined as person-centered, rather than domain-centered, expertise can range from knowing how a particular person reacts to a certain drug to knowing the personalities of family members and how the consumer reacts to them. Consumers described high quality clinical decision making as always in the context of this 'personal knowledge', i.e. 'He would never ask me to do that. He knows how nervous it would make me.'

Therefore, a provider with whom the consumer has a good relationship, especially one of long standing, will always take into account the myriad of relevant, personal details before recommending treatment. This sort of provider would never suggest a treatment that the patient could not tolerate or would not have selected. Consequently, consumers who believed this felt very little need to understand all the possible side effects or even to choose among available

treatment options. Several consumers believed that since the provider knew them so well, the right decision would certainly be made on their behalf by the provider and their preferences would be realized through the provider.

### **Sharing Information**

Providers were found to have a significant impact on a patients' willingness to disclose as well as how much, what, and in what way disclosing is done. A patient/provider relationship that is perceived by the patient as supportive, non-judgmental, and familiar creates the possibility for disclosing potentially disappointing or otherwise problematic information to the provider. Without such a relationship, important clinically relevant information is often withheld. Signs and symptoms experienced, as well as decisions about how to respond to them, are likely to be shared with providers only under the disclosure promoting conditions identified above.

The presence of evidence that disconfirms or the lack of evidence that confirms the existence of such a relationship results, frequently, in cautious or indirect disclosure, or nondisclosure. Significantly, one of the most difficult areas of disclosure is the lack of comfort with the provider. Cautious disclosure occurs when the consumer is testing the safety of disclosing and watching for a response. It generally involves giving responses that approximate what the provider wants to hear (as perceived by patient) yet opens the door for something else.

The provider's response is, in this instance, a powerful determinant of how the interaction proceeds and whether the elderly patient volunteers information that is contrary to what was hoped for. These offerings often come with qualifiers such as, 'Well, I think so..' or 'Probably' or 'I'm not really sure, but you're probably right.'

Silences were also used to avoid answering direct questions about following treatment instructions. These were especially common when the patient was unsure about the instructions or the questions being asked about symptoms. Silence and continued uncertainty over expectations was often seen as preferable to asking for clarification. Such a request could: reveal a deficiency in the patient, reveal the patient to be uncooperative, use up the providers time, or create more confusion.

When questioned about the possible consequences of continuing confusion and less than optimal treatment outcomes, elderly participants consistently insisted that their physicians were probably aware of what that patient was not revealing. There was a high level of faith in physicians ability to ‘read between the lines’, discerning what was not disclosed.

Other strategies used by elderly patients to reveal “unpleasant” information was to camouflage disclosure. This was especially true when making ‘veiled’ evaluative statements about the care. For example, it was common for frail elderly patients to comment that: “It must be difficult for you to work with someone so rude” or “My daughter was upset, but I’m not” or “It must be difficult to work in such a crowded place.”

### **PROVIDER COMPETENCE**

The majority of elderly consumers suggested that competence included remembering details about the patients life and medical histories. In fact, very elderly, chronically ill consumers clearly relied on the ability of providers to retain the details about medical histories that the consumer was unable to retain. When providers begin interactions with elderly patients by asking questions or making comments that demonstrated the possession of this personal,

biographical knowledge, this provided confirmation and evidence of expertise that the patient would be treated competently.

On the other hand, when a provider revealed an absence of such knowledge, often by asking the consumer questions deemed inappropriate by the consumer, the consumer perceived this to mean that the provider was not only uncaring, but may not be competent to make decisions about their care. Being asked to provide details about medical or personal history suggested that the provider was relying on the consumer's memory and ability to understand the medical complexities in order to determine treatment plans. It also suggested that the relationship was not what the consumer believed it to be. This created fear and was quite disappointing to the consumer.

Consistently, consumers expressed that they did not have the knowledge or understanding required to provide detailed information about their condition. They often became frightened when they believed the provider was relying on their ability to recall (or understand) such details accurately. Specific examples of when this was done, included the following:

- A woman described being asked what her name was by a provider she felt she had a close, long standing relationship with.
- A woman described how the provider confused her with someone else and she wondered if she was getting the other persons medications.
- Several consumers expressing profound disappointment in providers who had forgotten about illnesses or injuries that had occurred in the past, or forgotten about a reaction that the consumer had had to a certain drug.

None of the consumers who discussed these issues believed that providers should have to review their charts in order to remember these details.

Interviews with this group of consumers suggests that if patients are forced to choose between a provider whose technical competence has been questioned but who has a good relationship with the patient, and a provider who has better diagnostic and treatment skills, but who is less connected to the patient, most elderly consumers will select the former. The importance of the interactions with providers and the meanings attributed to these interactions could result in the unquestioned acceptance of poor outcomes and care that is poor quality by professional standards.

### **EVALUATING PROVIDER COMPETENCE**

There were a few instances in which retrospective assessments of the provider were altered by the acquisition of new information. A consumer who discovered later that a treatment, a medication, or a recommendation was not appropriate and may have even been harmful, reassessed the quality of both the care and the relationship. This reassessment involved a redefinition of the provider's commitment to or concern for the patient. Elderly consumers often interpreted inappropriate care as betrayal rather than evidence to reevaluate provider competence. A lack of competence was often explained by a new understanding of the relationship with the provider in which the provider did not 'really care' about the consumer.

There are several assumptions inherent in this reasoning: that physicians and other health care providers are aware of their limitations and know what they don't know, that providers have expertise in all areas and know how to obtain information they might need, and that providers know when a referral is appropriate. For elderly consumers interviewed, failure to do these things is more likely to demonstrate a lack of caring, than a lack of knowledge, skills or competence.

## **Referrals**

None of the elderly consumers interviewed for this study criticized past or present providers for continuing to treat them rather than referring them to an expert. [Different than physically disabled population] In general, these elderly subjects believed that when providers did not have adequate expertise to handle the situation, they should continue to treat them while obtaining the needed information from appropriate sources. Referrals were explained as 'going beyond what is necessary' and 'double-checking' the initial opinion; making extra sure that this is the right thing to do. It was explained as evidence that the primary provider is "so concerned about me that he is being over cautious." It was an acknowledgment of a caring relationship with the consumer rather competent clinical decision making.

## **PROTECTING PROVIDERS' FEELINGS**

The elderly group of consumers described an overall effort to be cooperative, and to do what the primary provider wanted them to do. Several consumers described 'going-along-with' decisions that they did not like or did not agree with. Most of these consumers did not consider it acceptable to ask questions, make suggestions, or openly disagree with the recommendations of their provider. A fear of upsetting others and the inability to come up with a 'reasonable' alternative were reasons given for 'going-along.'

Although a few were comfortable with open disagreement, most consumers would appear to agree, or, more often, just remain silent and then not follow the instructions. Rarely did any of these consumers reveal their intended lack of compliance to the provider. If the provider

discovered this it was generally because of feedback from family members or home health nurses.

Several consumers described instances in which they reported better outcomes (symptom relief) to providers than was actually the case because the patient did not want the provider to feel bad. This generally occurred when the patient felt that '(the provider) has done everything that could be done.' Providers were consequently 'protected' from failures and disappointing outcomes by elderly patients. It is easy to see how this can compromise the elderly patient's care.

When providers suggested to an elderly patient that a particular treatment would certainly be effective, patients described a reluctance to report failure and minimized problems or symptoms. Some consumers viewed this as protecting the doctor and some as hiding their own failure to respond 'correctly.' Not understanding that, in many instances, a variety of interventions must be tried before an effective one is discovered, patients often assumed that nothing more could be done unless they had been told there were other possibilities. Seeing a poor clinical response as a failure while assuming nothing else could be done, led to underreporting and minimizing of symptoms.

When a provider did let elderly consumers know that a 'failed or only partially effective treatment' was a possibility, and that it would not reflect badly on either the provider or the consumer, these consumers expressed a greater willingness to report.

Repeatedly, patients explained this as a strategy to spare the feelings of a provider who had done "everything possible." In some instances, patients described being uncomfortable giving such feedback since they were afraid they might be blamed, that the failure was somehow their fault. In other cases, the consumer translated the failed treatment as the providers lack of competence:

“..he gave me medication and said that it would work - and it didn't. I'm not going to tell him, though. I'm not going to tell him he's wrong or doesn't know what he's doing. My old physician, she was really good. She said 'This might work and it might not. This medication works for some people, but not for others. Medications are always an experiment.' ” (CONS040A, 9/96)

This was especially, but not exclusively, the case when directions had not been followed closely by the elderly consumer. This finding takes on even greater significance in the context of consumers' frequent reluctance to openly disagree with a proposed plan of care, even when they did not intend to follow through with it.

In these instances families were the ones most likely to insist that something needed to be done, and that the patient should not accept the outcome. Both families and patients interviewed for this study confirmed that families frequently played this role. In some cases, the consequence was that the family called, reported continuing problems, and made an appointment only to have the consumer appear in the clinic and deny that there were problems or that the problems were anything 'to worry about.'

## **CONSUMER GOALS**

Consumers all have personal goals that may not be *obviously* related to the illness and treatment plan or to the decisions made about care. For example, wanting to fatigue less easily, to sit for longer periods of time, to walk more quickly, to hold urine longer, and to pull oneself out of a chair were all goals related to spending time comfortably with family and friends. These abilities all relate to not making people wait, not forcing others to alter their plans, and not relying on assistance from others. These goals were often experienced by these elderly patients as more important than the goals providers were working towards. Not taking account of these

goals, or seeing them as a lesser priority, often resulted in patients not following instructions.

Not attending to these patients priorities was clearly seen to undermine the effectiveness of the entire treatment plan. Social workers were found to be very skilled at discovering these goals.

Another condition found repeatedly to undermine the patients willingness to cooperate with treatment was the presence of an unpleasant symptom that the patient attributed to treatment effects. The symptoms most often identified were: dizziness, constipation, and urinary incontinence. Other symptoms which caused patients to abandon or alter treatment plans included: weakness, sleepiness, nausea and fecal incontinence. These latter symptoms were no less troublesome. They were simply described as less frequently occurring.

Descriptions of their responses to these symptoms suggest that while patients sometimes report these symptoms without being questioned about them, they are much more likely to report them if they were warned about them in advance, and told that something could be done about them.

Several elderly patients reported altering many aspects of the treatment plan, changing or eliminating all of their medications, in an effort to discover the causative factor. Common strategies were to take less of everything or to not take medications a few times a week. This altered treatment plan was rarely shared with providers. Patients were more likely to report that: 'Sometimes I forget' or 'I do it pretty much right.'

In addition to personal goals of consumers, most elderly patients interviewed referred to the presence of goals, regardless of their specifics, as important to maintaining a sense of hope and a future to look forward to. Having something to work toward, at least theoretically, was seen as very significant. Consequently, the absence or worse, the removal, of goals to work for was experienced as an abandonment of hope and an assault on their sense of personal worth.

"Not worth investing in" was the interpretation that frequently resulted from the removal of services that had previously been explained as important. Becoming physically stronger, regaining physical abilities, (physical therapy) regardless of how useful the abilities were, constituted monumental triumphs emotionally.

While providers may see treatment and therapy changes as part of the 'normal' course of events, elderly patients often attributed quite different meanings to ending a treatment, cutting down on therapy, or stopping a medication. The meaning of these changes was often related to the way in which the treatment was originally proposed. The termination of something that was recommended as a way to maintain functionality or health was often perceived as giving up. The difficulty here for the provider is to sort out when the patient perceives the change as 'giving up' on them and when the patient would prefer a less intense program. These are, of course, not mutually exclusive.

### **PATIENT CHOICE AND DECISIONMAKING**

While wanting to appear cooperative, many frail, chronically ill, elderly consumers did express a desire that their wishes, goals, fears, intolerance's, sensitivities be central considerations in decisions made about their care. Many also expressed a desire to have their preferences acknowledged and implemented by others rather than being direct, active participants in the decision making. Consumers found comfort in the belief that their family members and their provider would make the right care decisions for them. This was especially true when the consumer did not understand the technical complexities or was too fatigued or too ill to participate in decision making.

Being able to accurately, sensitively, and comprehensively represent the consumers' view during decision making requires an intimate knowledge of both personal/biographical and medical details of the consumer's life. The inability to be actively involved, or the preference not to be involved, in important decisions increases the responsibility of other decision makers to present the consumers view. [Team issue] This is not equivalent to relying on a more generic or provider standards and assumptions. The providers' ability to do this is confounded by the frequent belief that standards of practice, safety concerns, or what the proxy decision maker considers sensible are acceptable substitutes for personal/biographical sensitivity.

Elderly consumers expressed the desire to be offered the opportunity to participate in a way that was not overly confusing, physically taxing, or personally intimidating. The desire not to anger, upset or disappoint providers and family members, the concern over 'getting someone (*specifically a well liked provider*) in trouble,' the confusion related to inadequate, or contradictory information, the physical, cognitive and emotional consequences of disease processes, and the often overwhelming amount and complexity of information were all identified as reasons not to be directly involved. These conditions were most likely to occur during times of stress, illness or sudden changes in condition. For these elderly subjects, an increase in illness/acuity resulted in less interest in being involved in decisionmaking. During these times they relied on family and caregivers to make appropriate decisions about their care.

There were several specific areas of decisionmaking that elderly subjects expressed a desire to be involved with. These included:

### **Choosing a Provider**

The choice of care or service provider was important to all consumers

interviewed. Personal care workers and primary care providers were mentioned most often, and most emphatically, as important choices. Consumers generally were able to exert choice in primary care provider (PCP), sometimes contrary to the advice and wishes of family members.

Very few had experienced choice in personal care worker (PCW) despite the significance of this relationship. Elderly consumers were unlikely to believe that choosing a PCW was possible. They were more likely to take what (who) they were given and make the best of it, or decline the service altogether if that was possible.

### **Choosing a Clinic**

Frail elderly consumers described several important considerations of clinic choice. These include:

- convenience of and comfort with location
- physical access
- staff familiarity with consumer (turnover in positions)
- adaptation of system to consumer peculiarities (without consumer request)
- provider knowledge/responsiveness to personal details
- having information available

While often unexpressed, these dimensions were consistently used by elderly consumers in evaluating the quality of the care they received and in determining their choice of clinic/provider.

The reluctance of many frail elderly patients to shift clinics and/or providers, even to follow-up on referrals, seemed often related, at least in part, to the significance of clinic staff. Even unpleasant clinic staff were sometimes preferred to someone new.

Elderly individuals talked repeatedly about the ‘wonderful’ care provided in places where staff made their familiarity with the patient quite obvious. This involved addressing the patient by name, making accommodations to preferences without reminders, i.e., “I know you always get cold, so I’ll put a heater in Room 2. You’ll have to wait a bit longer, but the room will be warm.” or “They seem to always lose your chart so I went over myself last night and told them to be sure the chart was here today.”

The areas these consumers identified as most significant were: comfort, availability of information, and acknowledgment of the relationship. Patients appreciated and were reassured by staff references to past events

### **Choice of Transportation**

Choice of transportation to and from provider offices and home and the day center was spontaneously brought up by almost all the elderly consumers. In several instances, consumers described how long, jarring bus rides in the morning could exhaust them before they even arrived to receive services. It was also very important to these consumers that drivers be familiar to them and knowledgeable about them. One family member mentioned the fact that the van driver in the morning knew that his mother liked her lap covered during the ride. Another described how important it was that the driver knew how to lift his wife so she would not be hurt. Only those individuals who knew her were able to do this.

### **DECLINING SERVICE/PARTICIPATION**

When services were declined, consumers often explained this to provider or others as a lack of need or ‘not feeling well today’ rather than expressing negative sentiments about the

provider or service. Often the consumer was unhappy with, fearful of, or confused by the service or provider but was reluctant to say so. Unwillingness to express negative sentiments was explained by:

- fear of retaliation
- fear of displeasing providers
- fear of being perceived as uncooperative or unappreciative
- fear of losing service altogether
- fear that the replacement will be worse

These fears were rarely spoken and required elaborate, indirect probing during the interviews to acquire this information. It would not be useful, in most instances, to ask for these assessments directly since the evaluations would not be forthcoming.

Consumer frequently described settling for services that they were unhappy with and, at times, declining the service altogether. This latter strategy was especially popular when a less desirable replacement was seen as no longer temporary.

There were some attempts made by elderly consumers and their family members to give feedback to staff and providers on a variety of topics. This was particularly true when consumers felt safe about doing so, with no fear of retaliation or disapproval. The feedback was still generally quite gentle and somewhat veiled.

One of the more common means of doing this was to 'just mention' something to the staff/provider the patient/family was most comfortable or familiar with. Frequently the person selected was a personal care worker, van driver, or day center staff. Comments were often camouflaged and delivered out of context so it would be difficult for the recipient of the message to appreciate the significance of a comment.

Many frail, elderly consumers also assume that these informal 'complaint/s' would be heard, understood, passed onto the appropriate person and formalized in a way that is not threatening. When questioned about this, consumers were all quite certain that 'mentioning' something in this way was tantamount to delivering the message to the provider who would most appreciate its significance. If there was no response to the 'mentioning', consumers assumed that a decision had been made to not respond because nothing could be done and/or it was not their (consumer's) place to comment.

The implications are clear for having clear, continuous communications among all staff and the importance of all staff being knowledgeable about symptoms.

### **POOR QUALITY CARE**

There were several descriptions of "poor care" in which procedures went smoothly, outcomes were specifically what the provider was trying to accomplish, but the care was experienced as impersonal or insensitive. This situation was almost always defined by consumers as reflecting poor quality care.

When asked to comment on care that was clearly not done well by professional standards by a provider with whom the consumer had a good relationship, the response was often to minimize the technical problem and refocus the evaluation on the intent and concern of the provider. For example, elderly consumers responded with comments such as, "it (the care) was the best that could be expected," or "...it's no one's fault...those things happen even to the most experienced doctors..." or "(provider) tried so hard. No one could have tried harder."

Even when there was no prior relationship with the providers involved, care that was experienced as sensitive, supportive and friendly was almost always evaluated by the consumer as high quality care, regardless of the outcome:

“...I mean, they did the best they could. And they were concerned. They had that..an attitude that was concerned, you know, that made me feel better to know that they were taking good care of me.” (CONS09, 181-184)

Exceptions to this were generally explained as difficulties the provider was experiencing rather than the consumer. For example, a staff person's rude behavior or a technical problem with a procedure might be described as what created problems for the provider. One woman commented about a receptionist, "It's terrible (for provider) that he has to work with people like that. She (receptionist) makes it hard for him....gets people mad at him."

When faced with evidence that their care may not have been appropriate, elderly patients often reported feeling badly for the provider who must surely be suffering as much as the patient over the 'unfortunate mistake':

“I can't remember what he said but what he said made you think he was concerned about how I felt. It was the touch and the attitude that he was doing the best he could.” (CONS04, 173-175)

Discoveries about inappropriate care were generally either accidental or forced by concerned family members rather than the result of patients themselves raising questions about the care and initiating a search for an explanation. In these circumstances, patients usually continued to defend the provider explaining that "mistakes happen" and that the provider must feel as badly about it as they did. For these patients, such an experience rarely raised doubts about the competence of the provider or concern over the quality of future care.

The explanation for accepting less than optimal care is generally assumed patient ignorance of what could be expected and the psychological need to believe the provider. This is not, however, an adequate explanation of the “logic” observed. Even patients who understood the clinical details of their care focused on the affective dimensions. A closer examination of patient discussions revealed a logical and consistent explanation for this.

### **HIGH QUALITY CARE**

Providers with whom elderly consumers had long histories and high quality interactions, were perceived as affectively motivated to provide high quality care. Consumers generally felt that such a provider, because of the established, caring, personal relationship, would always provide high quality care because the provider was affectively motivated to do so. Therefore, when a provider was affectively motivated, any failure to provide excellent care must be the consequence of factors beyond the control of that provider. A caring relationship was ipso facto both evidence and assurance of high quality care.

One consumer endured a very painful procedure for which she could have been safely and easily anesthetized. However, when she described the care, it was as the best care she had ever received. Her detailed description focused on how kind the physician and technician had been, how they had spoken with her throughout the procedure, making frequent eye contact while letting her know what was going on, and how they were sincerely disappointed at a negative outcome:

“The doctor stood by and the nurse was very, very helpful through the whole thing. She kinda talked me through it ‘cause it hurt so bad and was really, really good to me. And they were there too when I had to have my leg up with that sandbag on for eight hours at a time and it wasn’t their fault that the thing started

bleeding again...but they were very, very kind to me, both the nurses and the doctors. So I'd say that was one time that I had really good care." (CONS09A)

Other examples of high quality care were related to the motives attributed to providers behavior. In particular, taking time to stay with or visit with the patient, stopping by or calling "just to see how you are" (read) rather than because it is clinically indicated, checking up when it was not clinically necessary were all described as examples of excellent care. One consumer who had been extremely ill at home was visited by a physician who explained that "I just thought I'd stop by and say hello." The consumer took this quite literally as a socially, affectively motivated visit. This was her example of the 'best care' she had ever received.

Several other consumers made similar statements about visits from nurses and social workers. Each of these visits was planned as part of the follow-up care, although each provider had initiated the conversation with an exclamation of personal concern about the consumer.

Comments from consumers about the quality of care came repeatedly with descriptions about the quality of the provider-consumer relationship and what significance they believed the relationship had for the provider. Personal, biographical knowledge about the consumer, maintaining eye contact, using physical touch, and keeping confidences were used as consumer indicators of quality care. One of the important implications for the Partnership Program is the discovery of the magnitude and nature of significance of biographical expertise.

# **Quality Care: The Perspectives of Individuals with Physical Disabilities and their Caregivers**

*Completed in 1996, this narrative was a introductory report to the Partnership Program based on interviews with individuals with physical disabilities and their caregivers about care experiences. Subjects included individuals enrolled in the Partnership Program at Community Living Alliance, Madison.*

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## Introduction

The physically disabled consumers interviewed for this study provided remarkably consistent responses to questions about quality care in health care settings. Their responses suggested similarities in experiences across: disabilities, geographic areas, age, gender, health care funding sources, education, and income. The sample size was not large, nor was it sampled in a way that could support definitive statements about the extent and distribution of such experiences. However, the consistency of experiences across the sample at least suggests some common experiences, related primarily to having a disability. What is presented here is a summary of experiences and perceptions common to non-elderly individuals with permanent physical disabilities.

The issues repeatedly described by all participants as problematic when accessing and receiving quality care included:

- the inability of consumers to communicate effectively or participate satisfactorily in decisions about their care and treatment
- inadequate primary care provider (and other) expertise
- a lack of accommodation to disabilities in most health care settings
- a lack of centralized resources on disability related treatments, technologies, opportunities
- an incompatibility between the availability of resources/scheduling of services and other life demands (home and personal life)
- an incompatibility between managed care policies and the needs of physically disabled, and
- overall, consumer exhaustion and frustration as a consequence of tremendous work required *by the consumer* to access and use health care and other related services.

Discussions of the most significant and most problematic experiences with health care and health care providers were focused on physicians, personal care workers, and inpatient nursing staff. **It is extremely important for the reader to keep in mind the implications of the issues discussed below for physically disabled consumers with difficulty communicating verbally.**

## **Methods**

Data were collected and analyzed using the Grounded Theory method. Accordingly, interviews were initially quite open and unstructured, allowing the subjects to establish the topics to be pursued. A total of 45 interviews were conducted with physically disabled consumers and their caregivers. Interview subjects included disabled individuals, parents and spouses of disabled individuals and, in some cases, providers who serve these populations. Some consumer interviews were conducted individually, in person. These interviews were conducted once with follow up contacts for clarification. Other interviews were done over the Internet, collected from participants on various Internet listserv discussion groups (C-Palsy, Our-Kids, Teamwork).

The Internet subjects who volunteered to participate responded to a series of questions that were sent to them over a period of a few days to several weeks or months. The average age of adult physically disabled consumers responding via the Internet was 36. The most common physical disabilities for the entire group were cerebral palsy and spinal cord injury. There were 7 parents responding for their disabled children under age 18. The sample represents 14 states and 5 countries.

Subjects were encouraged to talk about health care experiences and how their disability and related services influenced other aspects of their lives. Following each new interview, an analysis was conducted and questions were altered accordingly. The consistency of topics

identified by consumers led quickly to a narrowing of the interviewers' focus. Remaining interviews were used to elaborate on these areas, each time also confirming the relevance of the topic.

Concurrent with interviewing, one of the researchers followed listserv conversations on various Internet disability related groups. This was done to track the topics discussed spontaneously by individuals with disabilities. It also provided continuing confirmation of the relevance of categories already identified while suggesting additional areas to pursue in subsequent interviews.

### **ABILITY (OPPORTUNITY) TO COMMUNICATE**

All consumers described situations in which they were not able to communicate effectively with health care providers or staff in health care settings. All consumers identified communication with providers as an important quality issue. Physically disabled consumers who had difficulty communicating verbally noted this particular issue as the most problematic for them.

One common perception discussed by several participants was that health care providers might describe a physically disabled individual as 'unable' to communicate, while physically disabled consumers frequently viewed those same experiences as 'not having an opportunity' to communicate. The distinction between these two perspectives is important, not just a question of semantics.

A provider's perception that a consumer's limitations preclude participation in the interaction is quite different from the consumer's perspective that there is no opportunity to participate. Consumers described what they viewed as factors undermining their ability to

communicate effectively, as opposed to accepting their physical limitations as an inherent inability to communicate. This latter interpretation, many said, was how they believed providers and staff often viewed them.

A lack of opportunity, on the other hand, suggests that there is something about the provider or the system that is preventing, either out of ignorance or insensitivity, the consumer's participation. It reflects on the character and quality of the provider and the system. The perception that providers or systems undermine opportunities leads to consumer anger, frustration, and mistrust. There is a more practical consequence to ineffective communication: the ability to communicate effectively is also the means by which other clinical outcomes can be reached.

The lack of opportunity to be understood clearly and efficiently prevents the consumer from contributing crucial historical information relevant to diagnosing and treating the presenting problem. The ability to participate in decision making, to state preferences, to provide important medical and personal information, and to develop a relationship with providers depends on the consumers' ability to communicate effectively. Undermining communication threatens each of these processes as well as an individual's sense of self.

### **Threat to Self**

Consumers who had difficulty communicating described encountering providers who seemed to interpret their physical disabilities and difficulty communicating as evidence of other impairments as well. In particular, consumers with communication disorders described providers and staff as equating difficulty speaking with low intelligence. They described provider responses to speech difficulty as: speaking in more simplistic terms, using smaller

words, speaking slowly and loudly, leaving consumers out of complicated discussions altogether, and making statements to others (whoever accompanied the consumer) suggesting the consumer's cognitive limitations.

Physically disabled consumers described how these discounting experiences excluded them from important discussions and assaulted their sense of who they are. This resulted in a generally poor quality interaction and unsatisfactory health care experience. Several physically disabled consumers expressed surprise that many of the health care providers they encountered were no less inclined to equate physical and communication difficulties with cognitive deficiencies than anyone else, and that these problems were as likely to occur in health care settings as anywhere else.

*When possible*, these physically disabled consumers attempted to remind others that they were not developmentally disabled. This, they hoped, would allow them to earn their way back into the conversation, to be consulted in decisions about their care, and would enable them to more accurately convey who they were and what they needed.

These consumers talked about the work they did to (1) convey to the provider who they are (intelligent, creative, funny, knowledgeable), and (2) make sure each new provider is adequately informed about their disability/illness or treatment. It was extremely important to all of these consumers that providers take the time to listen to and consider the consumers' knowledge, experiences with and wisdom about their disability. Consumers reported provider impatience with both purposes; seeming to busy or uninterested in who they are and uninterested, impatient or distrustful of what the consumer knows about the disability. While conveying a sense of humor, wide general knowledge, and high intelligence might seem irrelevant to the enterprise, consumers felt a sense of urgency over this.

Physically disabled consumers described several strategies they used to minimize the energy and the time required to communicate effectively, while maximizing the ability to convey important information. While the difficulties were most pronounced for consumers who had difficulty communicating verbally, these strategies were used by many disabled consumers without communication difficulties in order to participate more fully in their own health care. Sometimes these strategies are effective and sometimes they are not. Either way they are time consuming and often frustrating for the consumer.

Developing strategies and acquiring technologies to communicate effectively is an important criteria of quality for all of the individuals interviewed. The following section describes some of the ways consumers saw opportunities to communicate undermined and the strategies they developed in response.

## **STRATEGIES TO IMPROVE COMMUNICATION/CONSUMER PARTICIPATION**

### **Limit the Number of Providers**

Consumers reported limiting the number of providers whenever possible to avoid the necessity of starting over and repeating information. For consumers who had difficulty communicating verbally, not having to start dialogues over and struggle through an interaction at each appointment saved time, energy, and mistakes. Having consistency in providers minimized the need to keep starting over and, for many, minimized the danger of being excluded from decision making.

With very few exceptions, being able to see a consistent provider, rather than 'just getting in to see someone' was a high priority for the consumers interviewed,. However, several

consumers reported that office staff did not seem to appreciate this and would sometimes assign the most available provider rather than the one most familiar with the patient. For physically disabled consumers, with and without communication difficulty, this consistency was crucial.

This group reported great difficulty in negotiating with office staff to access their usual provider. The communication problems, exacerbated over the telephone, made such negotiation very problematic. Many of the consumers interviewed suggested that having direct access to their primary care provider, bypassing the office staff, or developing friendly, close relationships with office staff were some solutions to the difficulty in accessing their provider. However, the latter strategy, while fairly successful for some, necessitated more work for the consumer. It required an effort to nurture the relationship with staff, being very careful not to offend them, to be cheerful and friendly, and to put effort into maintaining those relationships at each contact. Obviously, turnover in providers and/or office staff is very significant.

### **Use Appointment Time Efficiently: Anticipate Discussions/Supplying a History**

Several participants with speech difficulty pointed out that appointment times in most health care organizations do not accommodate the special needs of people with disabilities. Many physically disabled consumers expressed a desire to increase the time they were allowed to spend with the health care provider, to slow the process down. Consumers were often torn between their efforts to convey important information while not using up too much time. They observed that provider were often impatient with the time it took them to interact.

“Docs seem especially stupid about people with speech disabilities, from my experience as a SL interpreter in medical settings. Often their attitude boils down to, "wait a minute, you mean it's going to take me an hour to do this history? I don't have an hour for you." Whenever I call for an appt for anything, I make a

point of saying, what's the std time for this appt; I want you to double it.  
(ICONS06, 11/95)

When a new provider was substituted for a more familiar provider, the problem was magnified to unmanageable proportions. This explains, in part, the significance of provider consistency.

Consumer strategies to use appointment time efficiently included: anticipating what information the provider would need from the consumer, what questions the provider would ask, what information would take time to retrieve in the charts or attain from others, and relating negative experiences from the past to prevent recurrences. Knowing that they would have to exchange as much information as possible in a short period of time, these consumers anticipated what would be needed as much as they could, maximizing the chances of having input and minimizing provider and consumer frustration.

Many consumers tried to have information written out in advance of an appointment. This would decrease the likelihood that tests would have to be repeated, that information would have to be collected again, that mistakes from the past would not be repeated, and that decisions would be based on accurate, complete, and up to date information. It also required a tremendous amount of preparation, including assistance from others:

“On the output side, I try to streamline things by providing the "S" in SOAP (Subjective, Objective, Assessment, Plan -- a little mnemonic for clinical practice). I prepare a "where I am now" report for each visit, with sections on current drugs (how they're tolerated, do I need refills...); things that have changed, things that stay the same, research update (I'll tell you what I've read and snagged from the net, you react), plan for next visit. I spit out a copy for the doc and then my chart, one for me & one for the advocate.” (ICONS06, 12/12/95)

Several participants maintained a copy of important information about their history, both personal and medical, and brought this with them to each provider encounter. This required a significant effort since most of them were doing this themselves rather than using a system established by the health care system or provider. One of the problems with this approach, described repeatedly by consumers, was the possibility that a provider might not read the information prepared and presented by the consumer. In several instances this prepared information was rejected in favor of a quicker conversation with whoever had accompanied the patient. The danger for consumers who prepared and presented information this way was that any inaccuracies in their histories could backfire on them by causing a provider to discount the patients information altogether. According to consumers, many providers may view these attempts by consumers as directive and intrusive rather than participatory and informative.

The consumers who described these occurrences were generally bewildered at the provider's lack of appreciation for the assistance they were providing. Stories told by consumers suggest a mismatch in what providers and consumers generally require as credible evidence for success or failure of a treatment. While the difference of opinion was obvious, the mismatch in evidential criteria was not apparent to most consumers. [This mismatch is described in more detail below in the section 'Becoming an Expert']

### **Using an Advocate**

Several physically disabled consumers brought an advocate with them to assist them in provider interactions. Intervention by the advocate was to restore the consumer's authority rather than for the advocate to take it on themselves. Some disabled individuals found it acceptable for the advocate to speak on their behalf, especially if their relationship was very close and the

advocate had sufficient knowledge of the patient to do so. However, a number of the subjects we talked to found this ‘substitution’ unacceptable. It was perceived as placing the consumer in a passive role, reinforcing the sense that they were not competent or could not participate effectively in decisions about their care.

Physically disabled consumers, as well as advocates for this population, focused on participation in/control over care related decisions as a central concern. The best advocate, according to this latter group, is the advocate who repeatedly directs the conversation back to the consumer, and facilitates the communication between the provider and the consumer. One risk of using this strategy is that the process could frustrate a provider who is attempting to speed up the tempo. According to the consumers interviewed, if the process becomes too difficult, the advocate has abandoned it altogether, communicating directly with the provider while marginalizing the consumer’s role.

All of the above strategies were described by the physically disabled consumers as ways to create opportunities to share information with their providers. Each strategy attempts to facilitate communications with the provider, make sure valuable personal and medical information about the consumer is known to the provider, and maintain the consumers position in the decision making process.

### **LACK OF PROVIDER EXPERTISE**

“I was having back pain and went to my primary care doctor who referred me to the so called specialist, a neurosurgeon in the managed care practice. He had little or no experience with someone with spina bifida, and couldn't believe I lived outside an institution. He had me get an MRI and when he saw my results, started recommending surgery, etc. When I asked questions, he admitted not knowing much about spina bifida.” (ICONS 21, IM.21)

“We have HMO so we need a PCP (who knows nothing at all about sci). He prescribes medicine that causes bloodclots, or causes muscle relaxation, or wants to sedate me all day; just to name a few. But by my insurance, I must see him first.” (ICONS01, 10-11-95)

“As PWDs, we get to be as (or more) expert in some parts of our bodies than the providers we see. If I want to, I can sound quite knowledgeable, which tends to piss docs off no end, tho nurses have no trouble with it.” (ICONS06, 11-30-95)

The physically disabled participants talked repeatedly about the lack of provider experience or expertise in the care of people with physical disabilities, both generally and specifically. There were occasional references made to internists or other primary care physicians who had developed expertise in the care of people with physical disabilities and consequently had many such patients in their practices. However, most of the consumers reported no such providers in their areas. Some of these providers were available on a referral basis at a great distance from home.

Providers most commonly identified as having appropriate expertise in physical disabilities were rehab specialist and urologists. Consumers who lived in areas where these specialists were available generally used them as primary care physicians:

“Never had the good fortune to see a physiatrist, but there are only a few specialties that cope well with a PWD(*person with disability*). In my experience, these include \*some\* PTs, \*some\* psychiatrists, \*some\* internists. Specialties which \*should\* have lots of exposure to the chronically ill -- rheumies, neuros, cardios -- have been dumber than most in my experience. (sigh.) It also depends a \*lot\* on the disability, and how one presents. (ICONS06, 11-30-95)

Consumers talked about the providers not having expertise in their particular disability and disabilities in general. Lack of expertise in a specific disability meant that providers were rarely informed about the most recent research on the topic, state of the art treatments, assistive

technology and equipment, and the nuances of how other health problems and medications might affect the disability and related treatment.

There were also many accounts of providers who were unaware of technology that could be very useful to the consumer. Many consumers expressed extreme frustration at consulting with providers, sometimes for several years, only to discover through some other means that there were in fact assistive technologies or treatments that were applicable to their condition. This story, in many forms, was repeated often. Some consumers described how they assumed their providers would tell them if an important treatment or device was available. Discovering later that such assistance was available but the provider was not aware of it left many consumers feeling distrustful of providers.

“Well, it took me about five years to come to grips with my disability. A county nurse made visits to see how I was doing about once a month and at the end of that five year period I began to wonder why there couldn’t be more done for me...so this lady got a hold of someone from the DVR...and in the summer of 1981 some fellow came to my house with a device to see if I could operate it. It’s a telephone operated with a puff and sip...to date there are nine people I call regularly...they enjoy it and so do I. It’s a lot of fun and its good therapy for me because of my high disability it keeps my lungs operating and filled.”  
(CONS01A, 27-63)

Consumers often saw this as a combination of ignorance and insensitivity since most consumers believed that providers were aware of their lack of knowledge about these things.

Several consumers also described being given contradictory information/advise from various ‘experts’ and other providers about their disability and its treatment. A new provider (referral, substitution, ER) often led to a recommendation to change a treatment plan or at least some part of it. Most consumers mentioned this spontaneously as a major frustration for them. All consumer agreed that this happened routinely. New treatment plans often did not take into

account special considerations related to the disability. Medications might be prescribed that are contraindicated with the particular disability or for that particular consumer. Consumers might be asked to engage in routines or treatments that either their disability, or the scheduling of supportive services, precluded. Examples of this would be a recommendation to 'soak in a bath' multiple times each day or for long periods, or to perform range of motion exercises requiring the presence of an assistant at times when there was none scheduled. Even having to take medications at times when there is no attendant available to help could create problems for physically disabled consumers.

There are two important issues to consider when new treatment plans are offered without experience or expertise in a particular consumer's disability in particular and life in general. First, there is the difficulty of following instructions that are incompatible with how a consumer's life might be scheduled. Second, there is the difficulty of making new demands on others. The ability to engage in the first must be balanced with the consequences for the second. In particular, consumers expressed reluctance to ask personal care workers to do more, to learn something new, or to alter a routine unless there was a significant reason to do so. Having to lift the consumer more often than usual in order to increase exercise time, take more frequent baths, or change positions more often increased the demand on the personal care worker and put them at greater risk. Consumers did not alter their schedules without reflecting on the possible consequences for themselves and others, and deciding whether engaging in the new routine was worth the price they would have to pay.

Responses to frequent contradictions in treatment included: losing faith in providers (in general), becoming an expert in their own disability, its treatment and new developments, taking control of decision making away from the provider whenever possible, and finding a provider

who would cooperate with them, who would acknowledge the consumer's expertise, experience, and preferences.

Losing faith in providers, and avoiding professionals whenever possible, is an option taken by many of the physically disabled consumers interviewed. This group could be characterized as frequently distrustful of providers' skill *and* intentions. A lack of expertise and information was often explained by consumers as reflecting a lack of caring or commitment, or as arrogance and insensitivity. Consumers believed that these providers were generally aware of their own limitations, and the knowledge they were lacking, but were unmotivated to do anything about the situation. This perception understandably led to a high level of distrust with providers and the system in general.

Descriptions of interactions with providers resulting in the consumer losing faith were often provided as examples of why providers could not generally be trusted. Consumers with this perspective avoided contact with health care providers whenever possible. When forced to have contact with health care providers and systems, these consumers tended to discount provider advice, pick selectively from advice given, or become confrontational and demanding. Each of these approaches undermines the effectiveness of health care and the quality of relationships with providers.

### **STRATEGIES FOR DEALING WITH LACK OF PROVIDER EXPERTISE**

Physically disabled consumers repeatedly described a variety of approaches they engaged in in response to a general lack of expertise. The efforts engaged in were often exhausting and time consuming. The ultimate goal was to find a knowledgeable and sensitive provider who

created opportunities for the consumer to participate while providing expert information and up-to-date knowledge of research and available technology.

### **Find a Provider with Experience/Expertise in Disability: Testing**

Prior to developing a relationship with a provider, consumers first searched for a provider who would be a good ‘partner’ with the consumer. As one consumer described in detail, the process often includes evaluating various facets of a providers practice, as well as reputation in the community:

“The first thing I do when searching for a personal physician is to ask the individuals whom I know well and respect their opinion. This includes asking our current physician. He knows our family, our needs, our likes and dislikes very well. Then I check their certification at the library. I also call their office to get a feel for how one is received and the policies specific to the office i.e. appointments, billing, physician coverage. For (daughter), I got the input of our local critical care physician, the SIDS Alliance, and MUMS network. Then went to the library. Then called the offices of the three physicians that we had narrowed our selection to. We went with the physician who personally returned our telephone call and openly expressed an interest in caring for (daughter) (all this with us knowing his private practice was closed to new patients).” (ICONS07, 2/12/96)

Several consumers reported 'trying out' new providers by ‘testing’ them. Physically disabled consumers noted the physical environments of a providers office - accessibility by wheelchair, appropriate space in waiting rooms, wide hallways, and wide office doorways. These were important factors in assessing a provider’s experience and sensitivity in care of people with physical disabilities.

Physically disabled consumers also made it a point to test providers by seeing if they were willing to refer to other providers more knowledgeable in a certain areas of care.

Reluctance to do so, despite not having adequate knowledge, was an indication that the provider

would not be a good partner. Willingness to refer tested several things at once: the providers general knowledge of the condition, their awareness of limitations in expertise, and their ability to work the system adequately, advocating for the consumer when necessary. *[This is also one of the reasons most frequently given for fear of managed care. There is a general perception that 1) primary care providers assigned to the consumer may have little expertise or interest in the consumer and the specific condition and 2) that the system has so many obstacles to quick referral that even the most committed providers may be prevented from making this work well.]*

In addition to the physical environment and willingness to refer, there were several things physically disabled consumers watched for and listened for when they were being treated in inpatient or outpatient settings. They observed a provider's body language, posture, eyes, and touch to determine if the provider was nervous or uncomfortable. They asked questions about the provider's background, as well as about their own disability, to see whether the provider was comfortable with consumer questions. This question and answer period also provided a forum in which the consumers could demonstrate their own expertise about their care. Whether or not, and with what response, the provider acknowledged this input was very important to physically disabled consumers and parents of physically disabled children.

"I think some providers (home health agencies and all others) are intimidated by disabled individuals. Most disabled individuals and/or their families tend to be pretty well informed about their conditions, and lots of people get defensive if they think we know more than they do. Perhaps that is because they know they are there to help us, and if we know more than they do, then they feel they can't help us." (ICONS09, 50-55)

### **Developing a Relationship with the Provider: Partnering**

An important part of the consumer-provider relationship is trust. For physically disabled consumers, both with and without communication difficulties, the development of trust in a provider was extremely important. Trust was closely intertwined with a provider demonstrating comfort with the consumer and the consumer's disability. An ongoing relationship provided the context in which the provider could, gradually and over time, get to know the consumer both medically and personally. Trust could only be developed over an extended period of time and as a consequence of many shared experiences.

Sometimes consumers selected providers who were not experts in their specific disability. These consumers reported that if providers do not have expertise in their disability, but are willing to become advocates for consumers, they can facilitate access to the information needed and refer when appropriate. Developing a relationship with a single provider minimizes the need for repetition of history including experience with ineffective and dangerous treatments in the past. It also allows the consumer to establish credibility with a provider, as well as establish their own identity as other than 'just disabled'.

### **Coaching**

When a provider is somewhat knowledgeable, the goal of many informed consumers is to negotiate care plans with the providers. This requires a close relationship in which the consumer has easy access to the provider. If a provider is at least somewhat accepting of the consumer's ability to identify needs and direct care, consumers engaged in coaching to increase the provider's skill. Coaching includes a blend of: informing, sharing relevant experiences, sharing success and

failures, motivating, encouraging, supporting and reinforcing. Consumers used this with a variety of providers including hospital staff who knew little about physical disabilities.

Coaching tended to be used with direct body care that required sustained effort and attention to detail with the consumers physical comfort as the outcome (inpatient settings). It also tended to occur in situations where the provider was being asked to do something in a way that differed from 'how it had always been done.' This applied to various providers including physicians, nurses and personal care workers.

## **Training**

This strategy was one that consisted primarily of providing information without engaging the provider at the level necessary for coaching. This included: supplying technical information, identifying resources, and even explaining disease processes and professional standards of practice for the disability or condition. A major component of training involved keeping providers up dated on emerging treatments and supportive technologies. While this required the consumer to maintain a tremendous amount of knowledge and a willingness to share that knowledge, it was much less demanding than the monitoring and vigilance required for coaching.

“I think that after health care workers talk to me they treat me differently than they would have. I look up all my medications in the PDR, I am familiar with medical lingo and have had eleven years to be intensely personal with my quadriplegic body. There are those in medicine that look at me sideways if I tell them I know when my bowel or bladder are stressed by the goosebumps I get--until they see them and see that I am right. “(10)

## **Demanding/Threatening**

“If someone doesn't listen, then I try a second time. If nothing then, then I will threaten to take my business elsewhere if they don't listen. If they don't, then I find a new doctor. For this to work, you also have to LISTEN to them.”  
(ICONS01, 2/7/96)

Some consumers described making clear demands and expressing displeasure as a strategy to change the way care was provided. This strategy was more likely to be used by consumers who did not feel terribly vulnerable to the possible consequences of their actions. These were usually consumers who had good backup systems, family, friends and/or a reliable care manager around. Sometimes the task took the form of hiring an attorney to generally oversee the process:

“My lawyer was involved a few times. A few faxes from him, and then the doctor started doing his job. I have only had to see him a few times. Normally now I just call and tell them I need a referral. They write it up without question now. That keeps my \*problems\* out of his office and off his fax machine.” (1)

Demanding can only be used by those consumers who have secure back-up systems, are not in immediate need of care by professionals, have the resources to maintain expertise, and are willing to fend for themselves. The number of consumers who opt for the last option when not in crisis explains much of the resistance to seeking professional care.

## **Dropping a Provider**

A small number of consumers described actually 'dropping' providers who would not listen to and integrate the consumers' concerns, both about 'medical' complications they had experienced and the impact of medical treatments on their lives. These consumers sometimes

engaged in searches for new, more responsive providers and sometimes sought answers to their questions from alternative or underground sources.

### **Develop Alternative System of Care**

Many other consumers used alternative therapies and traditional providers simultaneously, preserving the relationship with the traditional providers in case of an emergency requiring quick access to the health care system. Most consumers using this latter strategy did not share their use of these alternative therapies with their providers. This meant they had to manage two care systems and their possible interactions on their own.

### **Allowing Providers to Learn by Making Mistakes**

Some consumers were unwilling, unable, or lacking in sufficient resources to develop, implement, and monitor a parallel system of care. They could not risk alienating their provider. When their provider would not listen to them, consumers often went along with treatments that they knew, from experience, would not work. These consumers described 'suffering through' strategies, plans, and treatments that had caused problems for them in the past but allowed the provider to discover this for themselves. Even though the consumer had known this and made an effort to convey that information, several consumers noted that 'Once they see it happen a few times they start to respond differently.' Having to endure this anew with each new provider created frustration and anger for consumers. Physically disabled consumers with unusual or rare diseases and conditions reported having to 'let' providers make their own mistakes, at the consumer's expense more often than consumers with more 'usual' or common conditions.

As a result, many of these consumers had figured out, from past experiences, which experts they needed to access quickly in order to prevent rapid deterioration or the onset of a serious problem. This often involved seeing a pulmonary specialist or a urologist. Quick access to appropriate specialists is therefore one of the most important quality of care considerations for these consumers.

### **Becoming an Expert**

“Now I just make them explain something until I understand it. NOTHING is allowed to be done unless I know about and agree before it is done. (husband) and I have learned so much about what we need to know, that we tell them how to do the tests. We check out all things before. Right down to medicine. I never used to be allergic to anything. I am now. So we check out the possible side effects ahead of time. One doctor fought with us over the fact that a medicine was making me hair fall out in clumps. We spoke with the pharmacist and he checked all medicine and told me which one was doing it. It was in the PDR and the doctor didn't know it. Since then we take care of us!” (ICONS01)

One result of the lack of provider expertise in disabilities was that many consumers looked elsewhere for information and became experts themselves. Several consumers reported being connected to networks of individuals with disabilities in order to do this. Therefore, much of their information came from interacting with other consumers, reading newsletters, participating in Internet listservs, and being constantly vigilant for media reports of new developments. These were commonly cited sources of information.

The quality of the consumers' information is, of course, directly related to the quality of the source. While much of the information was derived from credible sources, consumers did not generally apply rigorous or consistent criteria to evaluating the quality of the information. Such an effort can increase the chances that care will be provided in a way that the consumer

prefers, or that takes account of new information. It also carries a risk, however. Consumers can expend significant time, energy and financial resources maintaining the expertise required to do this. They are also at risk for misinterpreting technical material and for attributing too much merit to an isolated experience that sounds promising. Many of the consumers interviewed were quite skilled at sorting through technical information. Their perspectives, however on what constitutes adequate evidence that a new treatment has some value, is quite different than criteria used by most providers.

This difference in attributing credibility to evidence created a considerable amount of conflict between consumers and providers and between consumers and organizations such as HMO's.

“A treatment that has been "proven" many times over, is not allowed because it is NOT on the LIST of acceptable medical treatments, regardless of the effectiveness or actual results, insurance companies will stand by and refuse payment of anything THEY deem "experimental". (ICONS08, 21-25)

It is worthwhile to look at the differences in how this occurs since it is a common source of conflict and becomes more of an issue as decision making about the credibility of (and therefore reimbursement for) new treatments is being taken out of the domain of the primary care providers, being often determined at an organizational level.

### **Lack of Resources**

Participants noted a lack of centralized resources on most disabilities. All consumers discussed the difficulty they experienced finding research and resource information. Many consumers complained about not being able to locate information and not being able to find a provider who could point them in the right direction. Resources and materials were widely

dispersed through local, state and federal health care and disability-related organizations, various on-going research projects, and Internet sources. Other complaints were finding materials only to learn they were outdated or not applicable to a consumers situation. This was especially true for consumers with multiple or unusual conditions.

### **Strategies To Deal With Lack Of Centralized Resources**

Several listservs devoted to specific disabilities and conditions served as clearinghouses for people with disabilities to share and exchange ideas. This was the most centralized resource for up to date information, however it is only accessible to those with Internet connectivity

“I know that getting information (at least about CP) can be hard. The bulk of information I've gotten, lately, about CP has been from the Cerebral Palsy listserv and the people on it. Before computers, I talked with people about their experiences, and still do. For more general medical information, I am fortunate to have a very aware doctor, we discuss my health, and he wants my opinions before he acts. Having his E-Mail address doesn't hurt either.” (ICONS14, 14F2)

“I ask questions. If I don't understand, then I ask my MIL (*mother-in-law*) who used to be a nurse. No answer. Then I hit the net, or the library. I keep looking until I have the answer.” (ICONS01, 2/7/96)

A tremendous amount of time and energy is expended by many consumers in keeping up with new developments.

### **LACK OF ACCOMMODATION TO DISABILITY IN MULTIPLE HEALTH CARE SETTINGS**

“If they do not come into contact with PWDs on a regular basis, they don't know how to respond, and often act inappropriately...I have been forced into situations where I have been exposed to providers that don't know how to deal with PWDs, and have had bad experiences. The most common "bad" things occur when they make assumptions about my abilities or health. The knowledgeable ones know

that very often we PWDs know more about our bodies than they do. The bad ones expect us to do what they say without question or input.” (16)

There was virtual consensus among consumers that most providers, other than those with expertise in rehabilitation medicine, have poor knowledge of, and experience with, treating individuals with physical disabilities. There was also consensus that many providers, and their staff, are uncomfortable with, uneasy around, or repulsed by persons with physical disabilities. This was a problem across health care settings, particularly in emergency rooms and hospital units other than rehab. It had a direct impact on the quality of the consumers experience.

### **Provider Discomfort**

Physically disabled consumers report a high level of sensitivity to what they perceived as generally unspoken cues conveyed by health care providers and others in reaction to their physical presence. These cues were seen primarily as 'distancing' behaviors such as avoiding eye contact, touching only when required by direct body work, and sitting at a distance beyond what is perceived as appropriate for social interaction.

These behaviors were experienced as maintaining distance between provider and recipient in response to feeling anything from discomfort to revulsion at the consumer's physical appearance. This had a tremendous impact on the nature, and therefore the quality, of the relationship. Although this discomfort (revulsion) was described as a more general obstacle to the development of any relationship, the focus of discussions have been on interactions with health care providers. Several of the subjects interviewed described the fear they experienced when seeking health care, especially on an urgent or emergency basis, from a provider whose

demeanor suggested discomfort with the consumer and/or with providing care. This behavior suggested a lack of knowledge, lack of caring, and was 'dehumanizing' to the consumer.

Some consumers spoke of their initial surprise that health care providers were not immune to such feelings and responses. These individuals attributed providers' discomfort to both their physical appearance and fear of not understanding how (or not wanting) to care for someone with serious disabilities.

### **Hospital Admissions**

Consumers entering the hospital were often forced to choose between a provider with expertise in the presenting problem or one with expertise in physical disabilities. These consumers described repeatedly how admission to units other than rehab led to the development of easily preventable disability-related problems that, when ignored, prolonged hospital stays and added pain, discomfort, and expense.

Several spinal cord injured (SCI) consumers described how they were often 'rescued' by rehab staff who had them transferred to the rehab unit regardless of the problem they were being treated for. This was most likely to occur after an acute episode had passed or post operation and after problems such as contractures or decubiti had already developed. Many consumer described requesting a transfer to rehab as soon as possible, especially if they had been hospitalized previously and had experienced problems. Moving to a rehab unit resulted in a loss of both nursing and medical expertise on what the consumer had been hospitalized for. This, of course, led to other problems because of the division of labor in hospital units.

Although theoretically possible, most consumers were unable to have access to experts in both the admitting diagnosis and rehabilitation unless the admission was directly related to the disability

### **Hospital/Clinic/ER Staff**

Another concern expressed by many of the subjects was what they perceived as inappropriate comments made by both hospital and clinic staff. These generally took the form of false reassurance, unrealistic expectations and unhelpful 'supportive' comments. For example, several consumers described how staff without experience in physical disabilities reassured them that a specific chronic problem they were having difficulty with would surely 'get better':

“When your put in a hospital, many nurses and other workers don't know what you have. Let alone what you can do. Like people coming in, and asking you to move your legs over this way. When my bladder started having spasms, nurses were happy: ‘That means your bladder is coming back’. They were happy, instead of seeing that meant more problems for me.” (ICONS01, 10-11-95)

A second and equally frustrating experience was when staff gave patients 'pep talks' about facing their disabilities or made comments that were out of synch with where the patient was emotionally. An example was to encourage someone to ‘keep fighting’, and ‘don’t give up’ when the patient had struggled and finally come to terms with the permanency of the situation. The lack of knowledge and therefore ability to match encouragement to a patient's stage of acceptance, and the routine of the illness, was mentioned several times in discussions of hospital admissions off the rehab units.

When staff and providers used ‘inappropriate’ language or made ‘unsuitable’ comments, the consumer was led to believe that the professionals providing care to him/her did not

understand the disability they were caring for, did not know how to appropriately treat the consumer, and, most importantly, did not appreciate the consumer's own level of understanding about the disability. Being cared for by providers and staff who were so inexperienced in the disability resulted in discomfort and fear for the physically disabled consumer.

### **Access to Records**

An experience described repeatedly was missing medical records and, consequently, inadequate disability related information for the staff providing care. This was a terrifying experience for all consumers, but especially for consumers with difficulty communicating. Medical records contain biographical information as well as personal medical history. If a provider was attempting to diagnose a physically disabled consumer without that information, the process often involved a standard exam which wasn't always most useful. This was exhausting for the provider and consumer. Consumers described this particular situation as one in which cognitive deficiencies were likely to be attributed to physically disabled consumers. In emergency situations there is often no advocate is with the patient to assist in communication. Most consumers reported that they avoided the emergency room whenever possible for fear of being treated by staff with no knowledge in treating people with disabilities.

### **INCOMPATIBILITY BETWEEN USE OF AVAILABLE RESOURCES/SCHEDULING AND OTHER LIFE DEMANDS**

"If people were going to take care of me, like a doctor or a nurse, they would have to know a lot about what I have, what I can do, what I can't do. What I can't do is a lot." (02A)

A focus on safety, a lack of provider awareness about the general impact of medical regimens and side effects, and the fear of litigation act in concert to keep the providers gaze away from the relationship between managing an illness and managing a life. For all of the consumers interviewed, life was infused with a constant balance between following useful treatment plans and having a meaningful life. Most consumers expressed a desire to negotiate this balance with providers rather than simply conforming to what they agreed were knowledgeable and helpful recommendations from the provider. As one parent explained, daily physical therapy for her 7 year old was important for the physical functioning of her child. However, following this regimen would result in loss of friends and a thwarted social and emotional life. This was an unacceptable tradeoff. It was important to be able to negotiate this explicitly with the provider rather than the alternatives which included lying to the provider or being perceived as uncooperative.

This balancing was most commonly experienced as a problem when a provider prescribed a treatment or care approach that would interfere with other activities considered by the consumer to be of central importance. Another example was prescribing a treatment that causes more sedation than the consumer is willing to live with, or sedation at a time when important activities are occurring. Parents of disabled children often discussed this in relation to the intrusiveness of therapy on their child's ability to engage in activities necessary for emotional and social development and the maintenance of friendships. Several emotional references were made to the unwillingness of many providers to negotiate around these important consumer concerns, to adapt or modify treatment, or to accommodate other, nonmedical needs.

## **INCOMPATIBILITY BETWEEN MANAGED CARE AND THE NEEDS OF PHYSICALLY DISABLED**

“My experience with managed care is that you need an advocate, and while its always better to be your own advocate, sometimes when you need the care most, you are least able to advocate (when you are sick, scared, and vulnerable).” 021-7/5/96-SMA-NE

“I fight with my managed care company constantly about durable medical equipment. They think an E&J chair that’s wide and heavy, and a foam rubber doughnut cushion should be just fine for me. I have had to be VERY well educated about my needs, and a strong advocate to get what I need. Otherwise, I would get whatever was on the shelf (and cheap).” 021-7/5-SMA-NE

A topic raised by several subjects, as well as present in many conversations on the Internet listservs, is the impact of managed care on the ability of people with physical disabilities to receive high quality care. In general, there is a fairly intense fear of managed care.

Physically disabled consumers anticipate, and have experienced, difficulties in managed care with access to their rehab physicians and related services. Although many physically disabled individuals consider their rehab physician to be their primary physician, this has often not been an option in HMO’s. Many consumers recounted stories of being assigned to primary care physicians who (1) have no experience with physically disabled individuals and (2) who do not have direct and reliable access to rehab consultants who can advise them on the care needs of this population:

“We have been in an HMO, and we were hampered at every turn in obtaining access to the specialists our daughter required....we were required to get a referral from her primary care doctor and request approval EACH time, even if the specialist himself had asked to see her in X number of months. The specialist was also not Board certified, which I feel was a minimal requirement for taking care of our child! (ICONS17, 2/1/96)

“As I indicated, my experience with managed care is mixed. Even when I have a problem which is referred to a specialist, its a "general" type specialist, not a specialist. My experience lately was with a neurosurgeon who never saw anyone

with spina bifida (he was definitely a slipped disk man) and so when he saw my MRI, he flipped. I demanded a referral to a neurosurgeon who was a spina bifida specialist (in this small city, there was all of one choice!) who said my problem was unrelated to spina bifida. I had a general urologist who never ordered the appropriate urodynamic testing, just kept checking my bladder for infections (which I did not have). Turns out I probably have had slow muscle loss over my life time which had never been addressed.” (ICONS19, 149-165)

In many cases, consumers believed it was not a matter of a provider not wanting to refer them, it was that the provider could not refer them according to organizational guidelines:

“The insistence that every person go only to a family physician ("primary care") makes no sense for a person with a severe disability that necessarily impacts all aspects of his/her care. This is actually NOT cost-effective, since invariably at least two visits are needed--one to get the referral to a specialist and then another to see the specialist who should have been called in the first place.” (ICONS22, 488-495)

“I have two brothers-in-law who are physicians. Both of them are continuously complaining that THEY are unable to provide the care for their patients that they feel their patients need. Their employers (HMOs) tell them whether or not they can ask for a specific test or treatment...My doctor fights very hard on my behalf, to get me the treatment and equipment we both agree I require.” (ICONS22, 56-68)

In addition to working with inappropriate providers, consumers described the multiple approval processes they endure in order to get equipment that fits their needs and lifestyle:

“Lastly, I fight with my managed care company constantly about durable medical equipment. They think an E&J chair that’s wide and heavy, and a foam rubber doughnut cushion should be just fine for me. I have had to be VERY well educated about my needs, and a strong advocate to get what I need. Otherwise, I would get whatever was on the shelf (and cheap). I’ve had to call, write them letters, and threaten to call the company president to get the appropriate equipment.”

The consequences, as described by subjects interviewed, have been: loss of consumer control/participation in decision making, delays in treatment, enduring what should have been a

preventable problem, frustration and lost time attempting to convince physicians that something is needed, and an increase in hospitalizations. Some individuals reported that these consequences have actually led primary care physicians to attend to the consumer's needs promptly the next time around, have made access to specialists much easier, and have increased the provider's respect for the consumers opinion. However, these are high costs for the consumers. Enduring the consequences of the primary providers lack of knowledge, frustration and anger, more often resulted in difficulty trusting the primary care provider. Several consumers described how much the relationship with the staff and the provider deteriorated as a consequence of these incidents.

## **PERSONAL CARE WORKERS**

Having a trusting, mutually respectful relationship with a primary care provider was found to be fundamental to quality of care for both the experience in general and the outcomes anticipated. The relationship identified as equal in significance to that with the primary care provider was the relationship with the personal care worker (PCW). This was especially the case for those consumers who had a high level of physical disability and/or difficulty communicating verbally:

“I don't take chances when it comes to (daughter). Once when we actually had a nursing assistant after (daughter)'s hip surgery, I got home one afternoon, and (daughter) was fussing in her hospital bed, and the assistant was laying on the couch sleeping. She didn't even wake up when I came into the living room and spoke to her!” (09-6/96-LMA-MW)

Physically disabled consumers spoke at length, and quite emotionally, about personal care and personal care workers. For those who relied on PCWs to carry out daily routines, the

PCW was at the center of both quality of care and quality of life. Also, quite impressive, was the amount of invisible (to providers) work that was done by consumers and their families to recruit, organize, and maintain a personal care system. Without such a system, life for consumers with extensive physical limitations came to a halt.

Analysis of the interviews with physically disabled consumers indicates that the most important PCW characteristics, in order of importance, are: 1) reliability, 2) comfort with disability and respect for the consumers, 3) safety, 4) hygiene, and 5) competence. Consumers reported frequently having to select personal care workers who did not meet all these criteria.

Under such conditions, consumers preferred to have PCWs who were at least reliable, e.g., they came to work at the scheduled time. Especially for consumers who depended on PCWs for ADLs, this characteristic was secured first. Comfort and safety were also important, although secondary. More than a few consumers kept PCWs they were actually afraid of or uncomfortable around because ‘at least they showed up.’ Hygiene (washing out urinals after use, hand washing) was hoped for but rarely expected. Competence was consistently the last priority **[this was not true of parents evaluating care of their children]**. It raises questions about the inconsistency between provider and consumer assessments of a good PCW.

The first challenge is finding reliable, well trained personal care workers. Consumers reported that this has become increasingly difficult. It requires more and more consumer time and energy to maintain. The difficulty and isolation of the work, in addition to the low wages, lack of benefits, and fragmented, unpredictable hours make it extremely difficult to recruit and maintain ‘good’ personal care workers.

## **Hiring a PCW**

According to both consumers and advocates in the Independent Living movement, it is very important for consumers with physical disabilities to be in charge of their personal care. The interviews with physically disabled consumers for this study suggest that this level of responsibility is not always the consumers preference. For some consumers under most conditions and for many consumers under some conditions, the preferred relationship is more of a partnership between an agency or individual and themselves; in hiring, training, oversight, evaluating and terminating PCWs.

Consumers who were the most physically disabled often expressed fear related to the vulnerable position they saw themselves in. These consumers expressed a clear preference for sharing the oversight, as well as the work involved in recruiting and training, with a person who had some formal authority, easier access to workers, and the backing of an organization. This was especially poignant when consumers were afraid to fire a PCW who was not performing well. One woman described how she ‘put up with’ a disrespectful, unreliable, unskilled PCW for a long time because she feared for her physical safety if she fired her. She was in the process of looking for an agency to take this responsibility; an agency that would take responsibility for a negative evaluation and fire the employee.

Other consumers, especially those who did not feel totally dependent on the PCW, were more willing to make some demands.

“I think when I get a new attendant I am more nervous than they are because I am in a great deal of pain and the stuff they have to do usually causes more of that. So if they are not skilled I suffer.” (ICONS22, 146-150)

Being part of a family, friend, or professional network that could provide some independent monitoring, back up when needed, and assurance of safety gave consumers much greater freedom to act on their evaluations.

“I designed my own handbook but incorporated a lot of the information I receive from the state. As a Human Resource major I am up on things like at will employment and labor law. I incorporated things like a contact system via my beeper should they be late picking me up at school or need me for any reason. I will be revising it to comply with Section 87.9174a of the Pennsylvania Attendant care act in the next few weeks.” (ICONS03, 3F52.1)

### **Advocates as Monitors**

Physically disabled consumers also spoke about the wisdom and effectiveness of having someone around who can monitor, at least in general, what is going on at home and intervene when necessary. Monitoring was described by subjects with and without communication difficulties. Intervention by the advocate is to restore the consumer's authority rather than for the person monitoring to take it on themselves.

For example, some subjects described how their spouse, or other relative (in most instances), scheduled their time at home to overlap with the time a personal care worker was there. This distant ‘surveillance’ was used to make sure things are going well without having direct involvement, unless necessary. Most of the consumers who talked about this monitoring function found it very reassuring. It also decreased the need for their own vigilance. Some subjects described case managers, other relatives, friends or even personal care workers as also serving in this role. Those who did not have such a person tended to place more emphasis and expend more energy on anticipating problems, planning for things going wrong, insuring that back up systems were in place, and worrying.

## **Reliability**

Being reliable is the most important attribute a personal care worker can have. Most physically disabled consumers are dependent on an attendant showing up each day on time. For most, the arrival of the PCW usually signals the start of the day and the time when a family caregiver can take a break. Many PCWs provide assistance and/or transportation to school and/or employment. Life cannot go on without them:

“However, due to our moving here to (rural area) and the problems we've had in keeping attendants, I \*have\* become weaker physically and mentally during the last two years just by worrying whether or if anyone would be coming to get me up or if my wife...would drag herself down by having to get me up or put me to bed if no one who is SUPPOSED to be scheduled comes.” 19-6/22-[SMA-SW]

The timing, sequencing, rhythm of the consumer's life is, in many instances, totally dependent on the personal care worker. Once a consumer begins to rely on a PCW, dependence is hard to break when they leave:

“Bad attendants, apart from doing poor work when they are here, are the ones that you cannot count on to be there when you expect them, or that just up and leave without telling you.” 022-5/15-LMA-WEST

## **Comfort/Able to communicate**

In the case of personal care workers, discomfort with a disability was problematic since the intensity of the relationship resulted in continual messages that the disabled person was 'unappealing'. Because these messages were often conveyed during physically intimate interactions, such negative messages were experienced as serious violations of usual expectations of intimacy in relationships.

"I can't talk or move so to be able to communicate is the most important thing and for them to remember is second, it's hard for me to remind them every time. Worst aide I had was about 4 years ago, I didn't have a computer and the only way I had to communicate was to spell everything using a headstick and point to letters on a board. My wife can keep it all straight in her head (I couldn't) but most people have to write down the letters to keep things straight. He figured if my wife could do it in her head so could he. To him it was like a game and he didn't care how many times I had to repeat things. It was a game to him, he would tell me "sooner or late I'll get it", even when I asked him "to write this down" he wouldn't. Finally I stopped trying and basically quit "talking" to him at all. I just stared at the TV all day. I became very slow to respond to anything, very depressed and quit feeding myself. My wife thought I had more problems from the stroke. Finally we got rid of him and my new aide "talked" with me. She wrote everything down, I almost never had to repeat anything, as a matter of fact she couldn't shut me up. I perked right up, started feeding myself, came out of my depression." 02-11-10-95

## **Training**

According to the consumers interviewed, it is unusual to find a personal care worker with prior training and experience in their particular type of physical disability. This means that, often, the physically disabled person or a family member must become the teacher. While this has some advantages for the consumer, providing direct input into how the care should be done, it is also exhausting for both the consumer and family member.

Many of the consumers interviewed have several part time personal care workers and must therefore engage in the same training program repeatedly. There is no opportunity for a group of PCWs to be trained simultaneously in a) a particular disability and 2) the consumer's personal preferences/needs of staff. When physically disabled consumers know that hiring a new PCW will require extensive training, this can be a significant deterrent to firing a PCW who is not doing high quality work.

## **Nature of the Work**

While many of the physically disabled subjects developed close relationships with personal care workers, this was not as likely to be in place of other friendships as it often was for elderly, homebound consumers.

The significance of personal care worker (PCW) relationships varied in relation to the richness of relationships in the consumers life. Individuals with active, diverse and satisfying interests and networks tended to use the relationship with PCWs more intimately than those lacking such connections:

“One naturally ends up being personally involved with ones attendants because of the extremely personal nature of the care they give. So it is even harder to admit to them that you are really not getting along or for some other reason must get rid of them. Also, since they work for very low wages and are thus almost all very low income workers, the job is necessarily extremely important to them.” (022-5/12/96-LMA-WEST)

## **Creating Back up Systems**

“Since I depend on other people and machines to replace what would otherwise be done by my own hands and feet, the most basic activities cannot be done if there is a failure in any system. If my personal assistant's car won't start on an icy January morning, I lie there watching the clock reminding myself that I'm lucky today wasn't the day I had to meet a client to wrap up a five-million-dollar account (not that I would ever be in a business that does that sort of thing). That's how it is--just trying to be a regular person becomes a moot point when a wheelchair drive belt snaps when you're two blocks away from home on the way to catch a bus to go to work. You just sit there in the street feeling ridiculous.” (ICONS20, 231-240)

The creativity and resourcefulness of many consumers was reflected in the elaborate back up systems they pieced together and maintained. This was not always possible, not did all consumers attempt to do this. Those who had the ability, the energy, and were determined to

continue a life that was not totally at the mercy of someone else's schedule, devised systems that could be activated when necessary.

Some of the strategies used by consumers included: devising ways to share PCWs with other consumers to increase the hours offered to the PCW, paying bonuses for quick response, lobbying for hours that were not really needed in order to give PCWs enough work to live on, and avoiding asking PCWs to engage in work they (the PCW) found distasteful. Consumers also described 'letting things go'; letting PCW behaviors or activities that the consumer didn't like (smoking, having friends over, etc.) take place. Many of these strategies involved breaking agency rules or policies or state statutes.

## **CONCLUSION**

It is clear from this study that consumers with physical disabilities often become active participants in their own care. This is often done in ways that are invisible to and sometimes problematic for health care providers and staff. Quality care for this group of consumers clearly reflects an understanding of how provider and agency decisions affect consumers personal lives.

# **Quality Care: The Perspectives of Individuals with Physical Disabilities and their Caregivers**

*Completed in 1996, this narrative was a introductory report to the Partnership Program based on interviews with individuals with physical disabilities and their caregivers about care experiences. Subjects included individuals enrolled in the Partnership Program at Community Living Alliance, Madison.*

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## Introduction

The physically disabled consumers interviewed for this study provided remarkably consistent responses to questions about quality care in health care settings. Their responses suggested similarities in experiences across: disabilities, geographic areas, age, gender, health care funding sources, education, and income. The sample size was not large, nor was it sampled in a way that could support definitive statements about the extent and distribution of such experiences. However, the consistency of experiences across the sample at least suggests some common experiences, related primarily to having a disability. What is presented here is a summary of experiences and perceptions common to non-elderly individuals with permanent physical disabilities.

The issues repeatedly described by all participants as problematic when accessing and receiving quality care included:

- the inability of consumers to communicate effectively or participate satisfactorily in decisions about their care and treatment
- inadequate primary care provider (and other) expertise
- a lack of accommodation to disabilities in most health care settings
- a lack of centralized resources on disability related treatments, technologies, opportunities
- an incompatibility between the availability of resources/scheduling of services and other life demands (home and personal life)
- an incompatibility between managed care policies and the needs of physically disabled, and
- overall, consumer exhaustion and frustration as a consequence of tremendous work required *by the consumer* to access and use health care and other related services.

Discussions of the most significant and most problematic experiences with health care and health care providers were focused on physicians, personal care workers, and inpatient nursing staff. **It is extremely important for the reader to keep in mind the implications of the issues discussed below for physically disabled consumers with difficulty communicating verbally.**

## **Methods**

Data were collected and analyzed using the Grounded Theory method. Accordingly, interviews were initially quite open and unstructured, allowing the subjects to establish the topics to be pursued. A total of 45 interviews were conducted with physically disabled consumers and their caregivers. Interview subjects included disabled individuals, parents and spouses of disabled individuals and, in some cases, providers who serve these populations. Some consumer interviews were conducted individually, in person. These interviews were conducted once with follow up contacts for clarification. Other interviews were done over the Internet, collected from participants on various Internet listserv discussion groups (C-Palsy, Our-Kids, Teamwork).

The Internet subjects who volunteered to participate responded to a series of questions that were sent to them over a period of a few days to several weeks or months. The average age of adult physically disabled consumers responding via the Internet was 36. The most common physical disabilities for the entire group were cerebral palsy and spinal cord injury. There were 7 parents responding for their disabled children under age 18. The sample represents 14 states and 5 countries.

Subjects were encouraged to talk about health care experiences and how their disability and related services influenced other aspects of their lives. Following each new interview, an analysis was conducted and questions were altered accordingly. The consistency of topics

identified by consumers led quickly to a narrowing of the interviewers' focus. Remaining interviews were used to elaborate on these areas, each time also confirming the relevance of the topic.

Concurrent with interviewing, one of the researchers followed listserv conversations on various Internet disability related groups. This was done to track the topics discussed spontaneously by individuals with disabilities. It also provided continuing confirmation of the relevance of categories already identified while suggesting additional areas to pursue in subsequent interviews.

### **ABILITY (OPPORTUNITY) TO COMMUNICATE**

All consumers described situations in which they were not able to communicate effectively with health care providers or staff in health care settings. All consumers identified communication with providers as an important quality issue. Physically disabled consumers who had difficulty communicating verbally noted this particular issue as the most problematic for them.

One common perception discussed by several participants was that health care providers might describe a physically disabled individual as 'unable' to communicate, while physically disabled consumers frequently viewed those same experiences as 'not having an opportunity' to communicate. The distinction between these two perspectives is important, not just a question of semantics.

A provider's perception that a consumer's limitations preclude participation in the interaction is quite different from the consumer's perspective that there is no opportunity to participate. Consumers described what they viewed as factors undermining their ability to

communicate effectively, as opposed to accepting their physical limitations as an inherent inability to communicate. This latter interpretation, many said, was how they believed providers and staff often viewed them.

A lack of opportunity, on the other hand, suggests that there is something about the provider or the system that is preventing, either out of ignorance or insensitivity, the consumer's participation. It reflects on the character and quality of the provider and the system. The perception that providers or systems undermine opportunities leads to consumer anger, frustration, and mistrust. There is a more practical consequence to ineffective communication: the ability to communicate effectively is also the means by which other clinical outcomes can be reached.

The lack of opportunity to be understood clearly and efficiently prevents the consumer from contributing crucial historical information relevant to diagnosing and treating the presenting problem. The ability to participate in decision making, to state preferences, to provide important medical and personal information, and to develop a relationship with providers depends on the consumers' ability to communicate effectively. Undermining communication threatens each of these processes as well as an individual's sense of self.

### **Threat to Self**

Consumers who had difficulty communicating described encountering providers who seemed to interpret their physical disabilities and difficulty communicating as evidence of other impairments as well. In particular, consumers with communication disorders described providers and staff as equating difficulty speaking with low intelligence. They described provider responses to speech difficulty as: speaking in more simplistic terms, using smaller

words, speaking slowly and loudly, leaving consumers out of complicated discussions altogether, and making statements to others (whoever accompanied the consumer) suggesting the consumer's cognitive limitations.

Physically disabled consumers described how these discounting experiences excluded them from important discussions and assaulted their sense of who they are. This resulted in a generally poor quality interaction and unsatisfactory health care experience. Several physically disabled consumers expressed surprise that many of the health care providers they encountered were no less inclined to equate physical and communication difficulties with cognitive deficiencies than anyone else, and that these problems were as likely to occur in health care settings as anywhere else.

*When possible*, these physically disabled consumers attempted to remind others that they were not developmentally disabled. This, they hoped, would allow them to earn their way back into the conversation, to be consulted in decisions about their care, and would enable them to more accurately convey who they were and what they needed.

These consumers talked about the work they did to (1) convey to the provider who they are (intelligent, creative, funny, knowledgeable), and (2) make sure each new provider is adequately informed about their disability/illness or treatment. It was extremely important to all of these consumers that providers take the time to listen to and consider the consumers' knowledge, experiences with and wisdom about their disability. Consumers reported provider impatience with both purposes; seeming to busy or uninterested in who they are and uninterested, impatient or distrustful of what the consumer knows about the disability. While conveying a sense of humor, wide general knowledge, and high intelligence might seem irrelevant to the enterprise, consumers felt a sense of urgency over this.

Physically disabled consumers described several strategies they used to minimize the energy and the time required to communicate effectively, while maximizing the ability to convey important information. While the difficulties were most pronounced for consumers who had difficulty communicating verbally, these strategies were used by many disabled consumers without communication difficulties in order to participate more fully in their own health care. Sometimes these strategies are effective and sometimes they are not. Either way they are time consuming and often frustrating for the consumer.

Developing strategies and acquiring technologies to communicate effectively is an important criteria of quality for all of the individuals interviewed. The following section describes some of the ways consumers saw opportunities to communicate undermined and the strategies they developed in response.

## **STRATEGIES TO IMPROVE COMMUNICATION/CONSUMER PARTICIPATION**

### **Limit the Number of Providers**

Consumers reported limiting the number of providers whenever possible to avoid the necessity of starting over and repeating information. For consumers who had difficulty communicating verbally, not having to start dialogues over and struggle through an interaction at each appointment saved time, energy, and mistakes. Having consistency in providers minimized the need to keep starting over and, for many, minimized the danger of being excluded from decision making.

With very few exceptions, being able to see a consistent provider, rather than 'just getting in to see someone' was a high priority for the consumers interviewed,. However, several

consumers reported that office staff did not seem to appreciate this and would sometimes assign the most available provider rather than the one most familiar with the patient. For physically disabled consumers, with and without communication difficulty, this consistency was crucial.

This group reported great difficulty in negotiating with office staff to access their usual provider. The communication problems, exacerbated over the telephone, made such negotiation very problematic. Many of the consumers interviewed suggested that having direct access to their primary care provider, bypassing the office staff, or developing friendly, close relationships with office staff were some solutions to the difficulty in accessing their provider. However, the latter strategy, while fairly successful for some, necessitated more work for the consumer. It required an effort to nurture the relationship with staff, being very careful not to offend them, to be cheerful and friendly, and to put effort into maintaining those relationships at each contact. Obviously, turnover in providers and/or office staff is very significant.

### **Use Appointment Time Efficiently: Anticipate Discussions/Supplying a History**

Several participants with speech difficulty pointed out that appointment times in most health care organizations do not accommodate the special needs of people with disabilities. Many physically disabled consumers expressed a desire to increase the time they were allowed to spend with the health care provider, to slow the process down. Consumers were often torn between their efforts to convey important information while not using up too much time. They observed that provider were often impatient with the time it took them to interact.

“Docs seem especially stupid about people with speech disabilities, from my experience as a SL interpreter in medical settings. Often their attitude boils down to, "wait a minute, you mean it's going to take me an hour to do this history? I don't have an hour for you." Whenever I call for an appt for anything, I make a

point of saying, what's the std time for this appt; I want you to double it.  
(ICONS06, 11/95)

When a new provider was substituted for a more familiar provider, the problem was magnified to unmanageable proportions. This explains, in part, the significance of provider consistency.

Consumer strategies to use appointment time efficiently included: anticipating what information the provider would need from the consumer, what questions the provider would ask, what information would take time to retrieve in the charts or attain from others, and relating negative experiences from the past to prevent recurrences. Knowing that they would have to exchange as much information as possible in a short period of time, these consumers anticipated what would be needed as much as they could, maximizing the chances of having input and minimizing provider and consumer frustration.

Many consumers tried to have information written out in advance of an appointment. This would decrease the likelihood that tests would have to be repeated, that information would have to be collected again, that mistakes from the past would not be repeated, and that decisions would be based on accurate, complete, and up to date information. It also required a tremendous amount of preparation, including assistance from others:

“On the output side, I try to streamline things by providing the "S" in SOAP (Subjective, Objective, Assessment, Plan -- a little mnemonic for clinical practice). I prepare a "where I am now" report for each visit, with sections on current drugs (how they're tolerated, do I need refills...); things that have changed, things that stay the same, research update (I'll tell you what I've read and snagged from the net, you react), plan for next visit. I spit out a copy for the doc and then my chart, one for me & one for the advocate.” (ICONS06, 12/12/95)

Several participants maintained a copy of important information about their history, both personal and medical, and brought this with them to each provider encounter. This required a significant effort since most of them were doing this themselves rather than using a system established by the health care system or provider. One of the problems with this approach, described repeatedly by consumers, was the possibility that a provider might not read the information prepared and presented by the consumer. In several instances this prepared information was rejected in favor of a quicker conversation with whoever had accompanied the patient. The danger for consumers who prepared and presented information this way was that any inaccuracies in their histories could backfire on them by causing a provider to discount the patients information altogether. According to consumers, many providers may view these attempts by consumers as directive and intrusive rather than participatory and informative.

The consumers who described these occurrences were generally bewildered at the provider's lack of appreciation for the assistance they were providing. Stories told by consumers suggest a mismatch in what providers and consumers generally require as credible evidence for success or failure of a treatment. While the difference of opinion was obvious, the mismatch in evidential criteria was not apparent to most consumers. [This mismatch is described in more detail below in the section 'Becoming an Expert']

### **Using an Advocate**

Several physically disabled consumers brought an advocate with them to assist them in provider interactions. Intervention by the advocate was to restore the consumer's authority rather than for the advocate to take it on themselves. Some disabled individuals found it acceptable for the advocate to speak on their behalf, especially if their relationship was very close and the

advocate had sufficient knowledge of the patient to do so. However, a number of the subjects we talked to found this ‘substitution’ unacceptable. It was perceived as placing the consumer in a passive role, reinforcing the sense that they were not competent or could not participate effectively in decisions about their care.

Physically disabled consumers, as well as advocates for this population, focused on participation in/control over care related decisions as a central concern. The best advocate, according to this latter group, is the advocate who repeatedly directs the conversation back to the consumer, and facilitates the communication between the provider and the consumer. One risk of using this strategy is that the process could frustrate a provider who is attempting to speed up the tempo. According to the consumers interviewed, if the process becomes too difficult, the advocate has abandoned it altogether, communicating directly with the provider while marginalizing the consumer’s role.

All of the above strategies were described by the physically disabled consumers as ways to create opportunities to share information with their providers. Each strategy attempts to facilitate communications with the provider, make sure valuable personal and medical information about the consumer is known to the provider, and maintain the consumers position in the decision making process.

### **LACK OF PROVIDER EXPERTISE**

“I was having back pain and went to my primary care doctor who referred me to the so called specialist, a neurosurgeon in the managed care practice. He had little or no experience with someone with spina bifida, and couldn't believe I lived outside an institution. He had me get an MRI and when he saw my results, started recommending surgery, etc. When I asked questions, he admitted not knowing much about spina bifida.” (ICONS 21, IM.21)

“We have HMO so we need a PCP (who knows nothing at all about sci). He prescribes medicine that causes bloodclots, or causes muscle relaxation, or wants to sedate me all day; just to name a few. But by my insurance, I must see him first.” (ICONS01, 10-11-95)

“As PWDs, we get to be as (or more) expert in some parts of our bodies than the providers we see. If I want to, I can sound quite knowledgeable, which tends to piss docs off no end, tho nurses have no trouble with it.” (ICONS06, 11-30-95)

The physically disabled participants talked repeatedly about the lack of provider experience or expertise in the care of people with physical disabilities, both generally and specifically. There were occasional references made to internists or other primary care physicians who had developed expertise in the care of people with physical disabilities and consequently had many such patients in their practices. However, most of the consumers reported no such providers in their areas. Some of these providers were available on a referral basis at a great distance from home.

Providers most commonly identified as having appropriate expertise in physical disabilities were rehab specialist and urologists. Consumers who lived in areas where these specialists were available generally used them as primary care physicians:

“Never had the good fortune to see a physiatrist, but there are only a few specialties that cope well with a PWD(*person with disability*). In my experience, these include *\*some\** PTs, *\*some\** psychiatrists, *\*some\** internists. Specialties which *\*should\** have lots of exposure to the chronically ill -- rheumies, neuros, cardios -- have been dumber than most in my experience. (sigh.) It also depends a *\*lot\** on the disability, and how one presents. (ICONS06, 11-30-95)

Consumers talked about the providers not having expertise in their particular disability and disabilities in general. Lack of expertise in a specific disability meant that providers were rarely informed about the most recent research on the topic, state of the art treatments, assistive

technology and equipment, and the nuances of how other health problems and medications might affect the disability and related treatment.

There were also many accounts of providers who were unaware of technology that could be very useful to the consumer. Many consumers expressed extreme frustration at consulting with providers, sometimes for several years, only to discover through some other means that there were in fact assistive technologies or treatments that were applicable to their condition. This story, in many forms, was repeated often. Some consumers described how they assumed their providers would tell them if an important treatment or device was available. Discovering later that such assistance was available but the provider was not aware of it left many consumers feeling distrustful of providers.

“Well, it took me about five years to come to grips with my disability. A county nurse made visits to see how I was doing about once a month and at the end of that five year period I began to wonder why there couldn’t be more done for me...so this lady got a hold of someone from the DVR...and in the summer of 1981 some fellow came to my house with a device to see if I could operate it. It’s a telephone operated with a puff and sip...to date there are nine people I call regularly...they enjoy it and so do I. It’s a lot of fun and its good therapy for me because of my high disability it keeps my lungs operating and filled.”  
(CONS01A, 27-63)

Consumers often saw this as a combination of ignorance and insensitivity since most consumers believed that providers were aware of their lack of knowledge about these things.

Several consumers also described being given contradictory information/advise from various ‘experts’ and other providers about their disability and its treatment. A new provider (referral, substitution, ER) often led to a recommendation to change a treatment plan or at least some part of it. Most consumers mentioned this spontaneously as a major frustration for them. All consumer agreed that this happened routinely. New treatment plans often did not take into

account special considerations related to the disability. Medications might be prescribed that are contraindicated with the particular disability or for that particular consumer. Consumers might be asked to engage in routines or treatments that either their disability, or the scheduling of supportive services, precluded. Examples of this would be a recommendation to 'soak in a bath' multiple times each day or for long periods, or to perform range of motion exercises requiring the presence of an assistant at times when there was none scheduled. Even having to take medications at times when there is no attendant available to help could create problems for physically disabled consumers.

There are two important issues to consider when new treatment plans are offered without experience or expertise in a particular consumer's disability in particular and life in general. First, there is the difficulty of following instructions that are incompatible with how a consumer's life might be scheduled. Second, there is the difficulty of making new demands on others. The ability to engage in the first must be balanced with the consequences for the second. In particular, consumers expressed reluctance to ask personal care workers to do more, to learn something new, or to alter a routine unless there was a significant reason to do so. Having to lift the consumer more often than usual in order to increase exercise time, take more frequent baths, or change positions more often increased the demand on the personal care worker and put them at greater risk. Consumers did not alter their schedules without reflecting on the possible consequences for themselves and others, and deciding whether engaging in the new routine was worth the price they would have to pay.

Responses to frequent contradictions in treatment included: losing faith in providers (in general), becoming an expert in their own disability, its treatment and new developments, taking control of decision making away from the provider whenever possible, and finding a provider

who would cooperate with them, who would acknowledge the consumer's expertise, experience, and preferences.

Losing faith in providers, and avoiding professionals whenever possible, is an option taken by many of the physically disabled consumers interviewed. This group could be characterized as frequently distrustful of providers' skill *and* intentions. A lack of expertise and information was often explained by consumers as reflecting a lack of caring or commitment, or as arrogance and insensitivity. Consumers believed that these providers were generally aware of their own limitations, and the knowledge they were lacking, but were unmotivated to do anything about the situation. This perception understandably led to a high level of distrust with providers and the system in general.

Descriptions of interactions with providers resulting in the consumer losing faith were often provided as examples of why providers could not generally be trusted. Consumers with this perspective avoided contact with health care providers whenever possible. When forced to have contact with health care providers and systems, these consumers tended to discount provider advice, pick selectively from advice given, or become confrontational and demanding. Each of these approaches undermines the effectiveness of health care and the quality of relationships with providers.

### **STRATEGIES FOR DEALING WITH LACK OF PROVIDER EXPERTISE**

Physically disabled consumers repeatedly described a variety of approaches they engaged in in response to a general lack of expertise. The efforts engaged in were often exhausting and time consuming. The ultimate goal was to find a knowledgeable and sensitive provider who

created opportunities for the consumer to participate while providing expert information and up-to-date knowledge of research and available technology.

### **Find a Provider with Experience/Expertise in Disability: Testing**

Prior to developing a relationship with a provider, consumers first searched for a provider who would be a good 'partner' with the consumer. As one consumer described in detail, the process often includes evaluating various facets of a providers practice, as well as reputation in the community:

"The first thing I do when searching for a personal physician is to ask the individuals whom I know well and respect their opinion. This includes asking our current physician. He knows our family, our needs, our likes and dislikes very well. Then I check their certification at the library. I also call their office to get a feel for how one is received and the policies specific to the office i.e. appointments, billing, physician coverage. For (daughter), I got the input of our local critical care physician, the SIDS Alliance, and MUMS network. Then went to the library. Then called the offices of the three physicians that we had narrowed our selection to. We went with the physician who personally returned our telephone call and openly expressed an interest in caring for (daughter) (all this with us knowing his private practice was closed to new patients)." (ICONS07, 2/12/96)

Several consumers reported 'trying out' new providers by 'testing' them. Physically disabled consumers noted the physical environments of a providers office - accessibility by wheelchair, appropriate space in waiting rooms, wide hallways, and wide office doorways. These were important factors in assessing a provider's experience and sensitivity in care of people with physical disabilities.

Physically disabled consumers also made it a point to test providers by seeing if they were willing to refer to other providers more knowledgeable in a certain areas of care.

Reluctance to do so, despite not having adequate knowledge, was an indication that the provider

would not be a good partner. Willingness to refer tested several things at once: the providers general knowledge of the condition, their awareness of limitations in expertise, and their ability to work the system adequately, advocating for the consumer when necessary. *[This is also one of the reasons most frequently given for fear of managed care. There is a general perception that 1) primary care providers assigned to the consumer may have little expertise or interest in the consumer and the specific condition and 2) that the system has so many obstacles to quick referral that even the most committed providers may be prevented from making this work well.]*

In addition to the physical environment and willingness to refer, there were several things physically disabled consumers watched for and listened for when they were being treated in inpatient or outpatient settings. They observed a provider's body language, posture, eyes, and touch to determine if the provider was nervous or uncomfortable. They asked questions about the provider's background, as well as about their own disability, to see whether the provider was comfortable with consumer questions. This question and answer period also provided a forum in which the consumers could demonstrate their own expertise about their care. Whether or not, and with what response, the provider acknowledged this input was very important to physically disabled consumers and parents of physically disabled children.

"I think some providers (home health agencies and all others) are intimidated by disabled individuals. Most disabled individuals and/or their families tend to be pretty well informed about their conditions, and lots of people get defensive if they think we know more than they do. Perhaps that is because they know they are there to help us, and if we know more than they do, then they feel they can't help us." (ICONS09, 50-55)

### **Developing a Relationship with the Provider: Partnering**

An important part of the consumer-provider relationship is trust. For physically disabled consumers, both with and without communication difficulties, the development of trust in a provider was extremely important. Trust was closely intertwined with a provider demonstrating comfort with the consumer and the consumer's disability. An ongoing relationship provided the context in which the provider could, gradually and over time, get to know the consumer both medically and personally. Trust could only be developed over an extended period of time and as a consequence of many shared experiences.

Sometimes consumers selected providers who were not experts in their specific disability. These consumers reported that if providers do not have expertise in their disability, but are willing to become advocates for consumers, they can facilitate access to the information needed and refer when appropriate. Developing a relationship with a single provider minimizes the need for repetition of history including experience with ineffective and dangerous treatments in the past. It also allows the consumer to establish credibility with a provider, as well as establish their own identity as other than 'just disabled'.

### **Coaching**

When a provider is somewhat knowledgeable, the goal of many informed consumers is to negotiate care plans with the providers. This requires a close relationship in which the consumer has easy access to the provider. If a provider is at least somewhat accepting of the consumer's ability to identify needs and direct care, consumers engaged in coaching to increase the provider's skill. Coaching includes a blend of: informing, sharing relevant experiences, sharing success and

failures, motivating, encouraging, supporting and reinforcing. Consumers used this with a variety of providers including hospital staff who knew little about physical disabilities.

Coaching tended to be used with direct body care that required sustained effort and attention to detail with the consumers physical comfort as the outcome (inpatient settings). It also tended to occur in situations where the provider was being asked to do something in a way that differed from 'how it had always been done.' This applied to various providers including physicians, nurses and personal care workers.

## **Training**

This strategy was one that consisted primarily of providing information without engaging the provider at the level necessary for coaching. This included: supplying technical information, identifying resources, and even explaining disease processes and professional standards of practice for the disability or condition. A major component of training involved keeping providers up dated on emerging treatments and supportive technologies. While this required the consumer to maintain a tremendous amount of knowledge and a willingness to share that knowledge, it was much less demanding than the monitoring and vigilance required for coaching.

“I think that after health care workers talk to me they treat me differently than they would have. I look up all my medications in the PDR, I am familiar with medical lingo and have had eleven years to be intensely personal with my quadriplegic body. There are those in medicine that look at me sideways if I tell them I know when my bowel or bladder are stressed by the goosebumps I get--until they see them and see that I am right. “(10)

## **Demanding/Threatening**

“If someone doesn't listen, then I try a second time. If nothing then, then I will threaten to take my business elsewhere if they don't listen. If they don't, then I find a new doctor. For this to work, you also have to LISTEN to them.”  
(ICONS01, 2/7/96)

Some consumers described making clear demands and expressing displeasure as a strategy to change the way care was provided. This strategy was more likely to be used by consumers who did not feel terribly vulnerable to the possible consequences of their actions. These were usually consumers who had good backup systems, family, friends and/or a reliable care manager around. Sometimes the task took the form of hiring an attorney to generally oversee the process:

“My lawyer was involved a few times. A few faxes from him, and then the doctor started doing his job. I have only had to see him a few times. Normally now I just call and tell them I need a referral. They write it up without question now. That keeps my \*problems\* out of his office and off his fax machine.” (1)

Demanding can only be used by those consumers who have secure back-up systems, are not in immediate need of care by professionals, have the resources to maintain expertise, and are willing to fend for themselves. The number of consumers who opt for the last option when not in crisis explains much of the resistance to seeking professional care.

## **Dropping a Provider**

A small number of consumers described actually 'dropping' providers who would not listen to and integrate the consumers' concerns, both about 'medical' complications they had experienced and the impact of medical treatments on their lives. These consumers sometimes

engaged in searches for new, more responsive providers and sometimes sought answers to their questions from alternative or underground sources.

### **Develop Alternative System of Care**

Many other consumers used alternative therapies and traditional providers simultaneously, preserving the relationship with the traditional providers in case of an emergency requiring quick access to the health care system. Most consumers using this latter strategy did not share their use of these alternative therapies with their providers. This meant they had to manage two care systems and their possible interactions on their own.

### **Allowing Providers to Learn by Making Mistakes**

Some consumers were unwilling, unable, or lacking in sufficient resources to develop, implement, and monitor a parallel system of care. They could not risk alienating their provider. When their provider would not listen to them, consumers often went along with treatments that they knew, from experience, would not work. These consumers described 'suffering through' strategies, plans, and treatments that had caused problems for them in the past but allowed the provider to discover this for themselves. Even though the consumer had known this and made an effort to convey that information, several consumers noted that 'Once they see it happen a few times they start to respond differently.' Having to endure this anew with each new provider created frustration and anger for consumers. Physically disabled consumers with unusual or rare diseases and conditions reported having to 'let' providers make their own mistakes, at the consumer's expense more often than consumers with more 'usual' or common conditions.

As a result, many of these consumers had figured out, from past experiences, which experts they needed to access quickly in order to prevent rapid deterioration or the onset of a serious problem. This often involved seeing a pulmonary specialist or a urologist. Quick access to appropriate specialists is therefore one of the most important quality of care considerations for these consumers.

### **Becoming an Expert**

“Now I just make them explain something until I understand it. NOTHING is allowed to be done unless I know about and agree before it is done. (husband) and I have learned so much about what we need to know, that we tell them how to do the tests. We check out all things before. Right down to medicine. I never used to be allergic to anything. I am now. So we check out the possible side effects ahead of time. One doctor fought with us over the fact that a medicine was making me hair fall out in clumps. We spoke with the pharmacist and he checked all medicine and told me which one was doing it. It was in the PDR and the doctor didn't know it. Since then we take care of us!” (ICONS01)

One result of the lack of provider expertise in disabilities was that many consumers looked elsewhere for information and became experts themselves. Several consumers reported being connected to networks of individuals with disabilities in order to do this. Therefore, much of their information came from interacting with other consumers, reading newsletters, participating in Internet listservs, and being constantly vigilant for media reports of new developments. These were commonly cited sources of information.

The quality of the consumers' information is, of course, directly related to the quality of the source. While much of the information was derived from credible sources, consumers did not generally apply rigorous or consistent criteria to evaluating the quality of the information. Such an effort can increase the chances that care will be provided in a way that the consumer

prefers, or that takes account of new information. It also carries a risk, however. Consumers can expend significant time, energy and financial resources maintaining the expertise required to do this. They are also at risk for misinterpreting technical material and for attributing too much merit to an isolated experience that sounds promising. Many of the consumers interviewed were quite skilled at sorting through technical information. Their perspectives, however on what constitutes adequate evidence that a new treatment has some value, is quite different than criteria used by most providers.

This difference in attributing credibility to evidence created a considerable amount of conflict between consumers and providers and between consumers and organizations such as HMO's.

“A treatment that has been "proven" many times over, is not allowed because it is NOT on the LIST of acceptable medical treatments, regardless of the effectiveness or actual results, insurance companies will stand by and refuse payment of anything THEY deem "experimental". (ICONS08, 21-25)

It is worthwhile to look at the differences in how this occurs since it is a common source of conflict and becomes more of an issue as decision making about the credibility of (and therefore reimbursement for) new treatments is being taken out of the domain of the primary care providers, being often determined at an organizational level.

### **Lack of Resources**

Participants noted a lack of centralized resources on most disabilities. All consumers discussed the difficulty they experienced finding research and resource information. Many consumers complained about not being able to locate information and not being able to find a provider who could point them in the right direction. Resources and materials were widely

dispersed through local, state and federal health care and disability-related organizations, various on-going research projects, and Internet sources. Other complaints were finding materials only to learn they were outdated or not applicable to a consumers situation. This was especially true for consumers with multiple or unusual conditions.

### **Strategies To Deal With Lack Of Centralized Resources**

Several listservs devoted to specific disabilities and conditions served as clearinghouses for people with disabilities to share and exchange ideas. This was the most centralized resource for up to date information, however it is only accessible to those with Internet connectivity

“I know that getting information (at least about CP) can be hard. The bulk of information I've gotten, lately, about CP has been from the Cerebral Palsy listserv and the people on it. Before computers, I talked with people about their experiences, and still do. For more general medical information, I am fortunate to have a very aware doctor, we discuss my health, and he wants my opinions before he acts. Having his E-Mail address doesn't hurt either.” (ICONS14, 14F2)

“I ask questions. If I don't understand, then I ask my MIL (*mother-in-law*) who used to be a nurse. No answer. Then I hit the net, or the library. I keep looking until I have the answer.” (ICONS01, 2/7/96)

A tremendous amount of time and energy is expended by many consumers in keeping up with new developments.

### **LACK OF ACCOMMODATION TO DISABILITY IN MULTIPLE HEALTH CARE SETTINGS**

“If they do not come into contact with PWDs on a regular basis, they don't know how to respond, and often act inappropriately...I have been forced into situations where I have been exposed to providers that don't know how to deal with PWDs, and have had bad experiences. The most common "bad" things occur when they make assumptions about my abilities or health. The knowledgeable ones know

that very often we PWDs know more about our bodies than they do. The bad ones expect us to do what they say without question or input.” (16)

There was virtual consensus among consumers that most providers, other than those with expertise in rehabilitation medicine, have poor knowledge of, and experience with, treating individuals with physical disabilities. There was also consensus that many providers, and their staff, are uncomfortable with, uneasy around, or repulsed by persons with physical disabilities. This was a problem across health care settings, particularly in emergency rooms and hospital units other than rehab. It had a direct impact on the quality of the consumers experience.

### **Provider Discomfort**

Physically disabled consumers report a high level of sensitivity to what they perceived as generally unspoken cues conveyed by health care providers and others in reaction to their physical presence. These cues were seen primarily as 'distancing' behaviors such as avoiding eye contact, touching only when required by direct body work, and sitting at a distance beyond what is perceived as appropriate for social interaction.

These behaviors were experienced as maintaining distance between provider and recipient in response to feeling anything from discomfort to revulsion at the consumer's physical appearance. This had a tremendous impact on the nature, and therefore the quality, of the relationship. Although this discomfort (revulsion) was described as a more general obstacle to the development of any relationship, the focus of discussions have been on interactions with health care providers. Several of the subjects interviewed described the fear they experienced when seeking health care, especially on an urgent or emergency basis, from a provider whose

demeanor suggested discomfort with the consumer and/or with providing care. This behavior suggested a lack of knowledge, lack of caring, and was 'dehumanizing' to the consumer.

Some consumers spoke of their initial surprise that health care providers were not immune to such feelings and responses. These individuals attributed providers' discomfort to both their physical appearance and fear of not understanding how (or not wanting) to care for someone with serious disabilities.

### **Hospital Admissions**

Consumers entering the hospital were often forced to choose between a provider with expertise in the presenting problem or one with expertise in physical disabilities. These consumers described repeatedly how admission to units other than rehab led to the development of easily preventable disability-related problems that, when ignored, prolonged hospital stays and added pain, discomfort, and expense.

Several spinal cord injured (SCI) consumers described how they were often 'rescued' by rehab staff who had them transferred to the rehab unit regardless of the problem they were being treated for. This was most likely to occur after an acute episode had passed or post operation and after problems such as contractures or decubiti had already developed. Many consumer described requesting a transfer to rehab as soon as possible, especially if they had been hospitalized previously and had experienced problems. Moving to a rehab unit resulted in a loss of both nursing and medical expertise on what the consumer had been hospitalized for. This, of course, led to other problems because of the division of labor in hospital units.

Although theoretically possible, most consumers were unable to have access to experts in both the admitting diagnosis and rehabilitation unless the admission was directly related to the disability

### **Hospital/Clinic/ER Staff**

Another concern expressed by many of the subjects was what they perceived as inappropriate comments made by both hospital and clinic staff. These generally took the form of false reassurance, unrealistic expectations and unhelpful 'supportive' comments. For example, several consumers described how staff without experience in physical disabilities reassured them that a specific chronic problem they were having difficulty with would surely 'get better':

“When your put in a hospital, many nurses and other workers don't know what you have. Let alone what you can do. Like people coming in, and asking you to move your legs over this way. When my bladder started having spasms, nurses were happy: ‘That means your bladder is coming back’. They were happy, instead of seeing that meant more problems for me.” (ICONS01, 10-11-95)

A second and equally frustrating experience was when staff gave patients 'pep talks' about facing their disabilities or made comments that were out of synch with where the patient was emotionally. An example was to encourage someone to ‘keep fighting’, and ‘don’t give up’ when the patient had struggled and finally come to terms with the permanency of the situation. The lack of knowledge and therefore ability to match encouragement to a patient's stage of acceptance, and the routine of the illness, was mentioned several times in discussions of hospital admissions off the rehab units.

When staff and providers used ‘inappropriate’ language or made ‘unsuitable’ comments, the consumer was led to believe that the professionals providing care to him/her did not

understand the disability they were caring for, did not know how to appropriately treat the consumer, and, most importantly, did not appreciate the consumer's own level of understanding about the disability. Being cared for by providers and staff who were so inexperienced in the disability resulted in discomfort and fear for the physically disabled consumer.

### **Access to Records**

An experience described repeatedly was missing medical records and, consequently, inadequate disability related information for the staff providing care. This was a terrifying experience for all consumers, but especially for consumers with difficulty communicating. Medical records contain biographical information as well as personal medical history. If a provider was attempting to diagnose a physically disabled consumer without that information, the process often involved a standard exam which wasn't always most useful. This was exhausting for the provider and consumer. Consumers described this particular situation as one in which cognitive deficiencies were likely to be attributed to physically disabled consumers. In emergency situations there is often no advocate is with the patient to assist in communication. Most consumers reported that they avoided the emergency room whenever possible for fear of being treated by staff with no knowledge in treating people with disabilities.

### **INCOMPATIBILITY BETWEEN USE OF AVAILABLE RESOURCES/SCHEDULING AND OTHER LIFE DEMANDS**

"If people were going to take care of me, like a doctor or a nurse, they would have to know a lot about what I have, what I can do, what I can't do. What I can't do is a lot." (02A)

A focus on safety, a lack of provider awareness about the general impact of medical regimens and side effects, and the fear of litigation act in concert to keep the providers gaze away from the relationship between managing an illness and managing a life. For all of the consumers interviewed, life was infused with a constant balance between following useful treatment plans and having a meaningful life. Most consumers expressed a desire to negotiate this balance with providers rather than simply conforming to what they agreed were knowledgeable and helpful recommendations from the provider. As one parent explained, daily physical therapy for her 7 year old was important for the physical functioning of her child. However, following this regimen would result in loss of friends and a thwarted social and emotional life. This was an unacceptable tradeoff. It was important to be able to negotiate this explicitly with the provider rather than the alternatives which included lying to the provider or being perceived as uncooperative.

This balancing was most commonly experienced as a problem when a provider prescribed a treatment or care approach that would interfere with other activities considered by the consumer to be of central importance. Another example was prescribing a treatment that causes more sedation than the consumer is willing to live with, or sedation at a time when important activities are occurring. Parents of disabled children often discussed this in relation to the intrusiveness of therapy on their child's ability to engage in activities necessary for emotional and social development and the maintenance of friendships. Several emotional references were made to the unwillingness of many providers to negotiate around these important consumer concerns, to adapt or modify treatment, or to accommodate other, nonmedical needs.

## **INCOMPATIBILITY BETWEEN MANAGED CARE AND THE NEEDS OF PHYSICALLY DISABLED**

“My experience with managed care is that you need an advocate, and while its always better to be your own advocate, sometimes when you need the care most, you are least able to advocate (when you are sick, scared, and vulnerable).” 021-7/5/96-SMA-NE

“I fight with my managed care company constantly about durable medical equipment. They think an E&J chair that’s wide and heavy, and a foam rubber doughnut cushion should be just fine for me. I have had to be VERY well educated about my needs, and a strong advocate to get what I need. Otherwise, I would get whatever was on the shelf (and cheap).” 021-7/5-SMA-NE

A topic raised by several subjects, as well as present in many conversations on the Internet listservs, is the impact of managed care on the ability of people with physical disabilities to receive high quality care. In general, there is a fairly intense fear of managed care.

Physically disabled consumers anticipate, and have experienced, difficulties in managed care with access to their rehab physicians and related services. Although many physically disabled individuals consider their rehab physician to be their primary physician, this has often not been an option in HMO’s. Many consumers recounted stories of being assigned to primary care physicians who (1) have no experience with physically disabled individuals and (2) who do not have direct and reliable access to rehab consultants who can advise them on the care needs of this population:

“We have been in an HMO, and we were hampered at every turn in obtaining access to the specialists our daughter required....we were required to get a referral from her primary care doctor and request approval EACH time, even if the specialist himself had asked to see her in X number of months. The specialist was also not Board certified, which I feel was a minimal requirement for taking care of our child! (ICONS17, 2/1/96)

“As I indicated, my experience with managed care is mixed. Even when I have a problem which is referred to a specialist, its a "general" type specialist, not a specialist. My experience lately was with a neurosurgeon who never saw anyone

with spina bifida (he was definitely a slipped disk man) and so when he saw my MRI, he flipped. I demanded a referral to a neurosurgeon who was a spina bifida specialist (in this small city, there was all of one choice!) who said my problem was unrelated to spina bifida. I had a general urologist who never ordered the appropriate urodynamic testing, just kept checking my bladder for infections (which I did not have). Turns out I probably have had slow muscle loss over my life time which had never been addressed.” (ICONS19, 149-165)

In many cases, consumers believed it was not a matter of a provider not wanting to refer them, it was that the provider could not refer them according to organizational guidelines:

“The insistence that every person go only to a family physician ("primary care") makes no sense for a person with a severe disability that necessarily impacts all aspects of his/her care. This is actually NOT cost-effective, since invariably at least two visits are needed--one to get the referral to a specialist and then another to see the specialist who should have been called in the first place.” (ICONS22, 488-495)

“I have two brothers-in-law who are physicians. Both of them are continuously complaining that THEY are unable to provide the care for their patients that they feel their patients need. Their employers (HMOs) tell them whether or not they can ask for a specific test or treatment...My doctor fights very hard on my behalf, to get me the treatment and equipment we both agree I require.” (ICONS22, 56-68)

In addition to working with inappropriate providers, consumers described the multiple approval processes they endure in order to get equipment that fits their needs and lifestyle:

“Lastly, I fight with my managed care company constantly about durable medical equipment. They think an E&J chair that’s wide and heavy, and a foam rubber doughnut cushion should be just fine for me. I have had to be VERY well educated about my needs, and a strong advocate to get what I need. Otherwise, I would get whatever was on the shelf (and cheap). I’ve had to call, write them letters, and threaten to call the company president to get the appropriate equipment.”

The consequences, as described by subjects interviewed, have been: loss of consumer control/participation in decision making, delays in treatment, enduring what should have been a

preventable problem, frustration and lost time attempting to convince physicians that something is needed, and an increase in hospitalizations. Some individuals reported that these consequences have actually led primary care physicians to attend to the consumer's needs promptly the next time around, have made access to specialists much easier, and have increased the provider's respect for the consumers opinion. However, these are high costs for the consumers. Enduring the consequences of the primary providers lack of knowledge, frustration and anger, more often resulted in difficulty trusting the primary care provider. Several consumers described how much the relationship with the staff and the provider deteriorated as a consequence of these incidents.

## **PERSONAL CARE WORKERS**

Having a trusting, mutually respectful relationship with a primary care provider was found to be fundamental to quality of care for both the experience in general and the outcomes anticipated. The relationship identified as equal in significance to that with the primary care provider was the relationship with the personal care worker (PCW). This was especially the case for those consumers who had a high level of physical disability and/or difficulty communicating verbally:

“I don't take chances when it comes to (daughter). Once when we actually had a nursing assistant after (daughter)'s hip surgery, I got home one afternoon, and (daughter) was fussing in her hospital bed, and the assistant was laying on the couch sleeping. She didn't even wake up when I came into the living room and spoke to her!” (09-6/96-LMA-MW)

Physically disabled consumers spoke at length, and quite emotionally, about personal care and personal care workers. For those who relied on PCWs to carry out daily routines, the

PCW was at the center of both quality of care and quality of life. Also, quite impressive, was the amount of invisible (to providers) work that was done by consumers and their families to recruit, organize, and maintain a personal care system. Without such a system, life for consumers with extensive physical limitations came to a halt.

Analysis of the interviews with physically disabled consumers indicates that the most important PCW characteristics, in order of importance, are: 1) reliability, 2) comfort with disability and respect for the consumers, 3) safety, 4) hygiene, and 5) competence. Consumers reported frequently having to select personal care workers who did not meet all these criteria.

Under such conditions, consumers preferred to have PCWs who were at least reliable, e.g., they came to work at the scheduled time. Especially for consumers who depended on PCWs for ADLs, this characteristic was secured first. Comfort and safety were also important, although secondary. More than a few consumers kept PCWs they were actually afraid of or uncomfortable around because ‘at least they showed up.’ Hygiene (washing out urinals after use, hand washing) was hoped for but rarely expected. Competence was consistently the last priority **[this was not true of parents evaluating care of their children]**. It raises questions about the inconsistency between provider and consumer assessments of a good PCW.

The first challenge is finding reliable, well trained personal care workers. Consumers reported that this has become increasingly difficult. It requires more and more consumer time and energy to maintain. The difficulty and isolation of the work, in addition to the low wages, lack of benefits, and fragmented, unpredictable hours make it extremely difficult to recruit and maintain ‘good’ personal care workers.

## **Hiring a PCW**

According to both consumers and advocates in the Independent Living movement, it is very important for consumers with physical disabilities to be in charge of their personal care. The interviews with physically disabled consumers for this study suggest that this level of responsibility is not always the consumers preference. For some consumers under most conditions and for many consumers under some conditions, the preferred relationship is more of a partnership between an agency or individual and themselves; in hiring, training, oversight, evaluating and terminating PCWs.

Consumers who were the most physically disabled often expressed fear related to the vulnerable position they saw themselves in. These consumers expressed a clear preference for sharing the oversight, as well as the work involved in recruiting and training, with a person who had some formal authority, easier access to workers, and the backing of an organization. This was especially poignant when consumers were afraid to fire a PCW who was not performing well. One woman described how she ‘put up with’ a disrespectful, unreliable, unskilled PCW for a long time because she feared for her physical safety if she fired her. She was in the process of looking for an agency to take this responsibility; an agency that would take responsibility for a negative evaluation and fire the employee.

Other consumers, especially those who did not feel totally dependent on the PCW, were more willing to make some demands.

“I think when I get a new attendant I am more nervous than they are because I am in a great deal of pain and the stuff they have to do usually causes more of that. So if they are not skilled I suffer.” (ICONS22, 146-150)

Being part of a family, friend, or professional network that could provide some independent monitoring, back up when needed, and assurance of safety gave consumers much greater freedom to act on their evaluations.

“I designed my own handbook but incorporated a lot of the information I receive from the state. As a Human Resource major I am up on things like at will employment and labor law. I incorporated things like a contact system via my beeper should they be late picking me up at school or need me for any reason. I will be revising it to comply with Section 87.9174a of the Pennsylvania Attendant care act in the next few weeks.” (ICONS03, 3F52.1)

### **Advocates as Monitors**

Physically disabled consumers also spoke about the wisdom and effectiveness of having someone around who can monitor, at least in general, what is going on at home and intervene when necessary. Monitoring was described by subjects with and without communication difficulties. Intervention by the advocate is to restore the consumer's authority rather than for the person monitoring to take it on themselves.

For example, some subjects described how their spouse, or other relative (in most instances), scheduled their time at home to overlap with the time a personal care worker was there. This distant ‘surveillance’ was used to make sure things are going well without having direct involvement, unless necessary. Most of the consumers who talked about this monitoring function found it very reassuring. It also decreased the need for their own vigilance. Some subjects described case managers, other relatives, friends or even personal care workers as also serving in this role. Those who did not have such a person tended to place more emphasis and expend more energy on anticipating problems, planning for things going wrong, insuring that back up systems were in place, and worrying.

## **Reliability**

Being reliable is the most important attribute a personal care worker can have. Most physically disabled consumers are dependent on an attendant showing up each day on time. For most, the arrival of the PCW usually signals the start of the day and the time when a family caregiver can take a break. Many PCWs provide assistance and/or transportation to school and/or employment. Life cannot go on without them:

“However, due to our moving here to (rural area) and the problems we've had in keeping attendants, I \*have\* become weaker physically and mentally during the last two years just by worrying whether or if anyone would be coming to get me up or if my wife...would drag herself down by having to get me up or put me to bed if no one who is SUPPOSED to be scheduled comes.” 19-6/22-[SMA-SW]

The timing, sequencing, rhythm of the consumer's life is, in many instances, totally dependent on the personal care worker. Once a consumer begins to rely on a PCW, dependence is hard to break when they leave:

“Bad attendants, apart from doing poor work when they are here, are the ones that you cannot count on to be there when you expect them, or that just up and leave without telling you.” 022-5/15-LMA-WEST

## **Comfort/Able to communicate**

In the case of personal care workers, discomfort with a disability was problematic since the intensity of the relationship resulted in continual messages that the disabled person was 'unappealing'. Because these messages were often conveyed during physically intimate interactions, such negative messages were experienced as serious violations of usual expectations of intimacy in relationships.

"I can't talk or move so to be able to communicate is the most important thing and for them to remember is second, it's hard for me to remind them every time. Worst aide I had was about 4 years ago, I didn't have a computer and the only way I had to communicate was to spell everything using a headstick and point to letters on a board. My wife can keep it all straight in her head (I couldn't) but most people have to write down the letters to keep things straight. He figured if my wife could do it in her head so could he. To him it was like a game and he didn't care how many times I had to repeat things. It was a game to him, he would tell me "sooner or late I'll get it", even when I asked him "to write this down" he wouldn't. Finally I stopped trying and basically quit "talking" to him at all. I just stared at the TV all day. I became very slow to respond to anything, very depressed and quit feeding myself. My wife thought I had more problems from the stroke. Finally we got rid of him and my new aide "talked" with me. She wrote everything down, I almost never had to repeat anything, as a matter of fact she couldn't shut me up. I perked right up, started feeding myself, came out of my depression." 02-11-10-95

## **Training**

According to the consumers interviewed, it is unusual to find a personal care worker with prior training and experience in their particular type of physical disability. This means that, often, the physically disabled person or a family member must become the teacher. While this has some advantages for the consumer, providing direct input into how the care should be done, it is also exhausting for both the consumer and family member.

Many of the consumers interviewed have several part time personal care workers and must therefore engage in the same training program repeatedly. There is no opportunity for a group of PCWs to be trained simultaneously in a) a particular disability and 2) the consumer's personal preferences/needs of staff. When physically disabled consumers know that hiring a new PCW will require extensive training, this can be a significant deterrent to firing a PCW who is not doing high quality work.

## **Nature of the Work**

While many of the physically disabled subjects developed close relationships with personal care workers, this was not as likely to be in place of other friendships as it often was for elderly, homebound consumers.

The significance of personal care worker (PCW) relationships varied in relation to the richness of relationships in the consumers life. Individuals with active, diverse and satisfying interests and networks tended to use the relationship with PCWs more intimately than those lacking such connections:

“One naturally ends up being personally involved with ones attendants because of the extremely personal nature of the care they give. So it is even harder to admit to them that you are really not getting along or for some other reason must get rid of them. Also, since they work for very low wages and are thus almost all very low income workers, the job is necessarily extremely important to them.” (022-5/12/96-LMA-WEST)

## **Creating Back up Systems**

“Since I depend on other people and machines to replace what would otherwise be done by my own hands and feet, the most basic activities cannot be done if there is a failure in any system. If my personal assistant's car won't start on an icy January morning, I lie there watching the clock reminding myself that I'm lucky today wasn't the day I had to meet a client to wrap up a five-million-dollar account (not that I would ever be in a business that does that sort of thing). That's how it is--just trying to be a regular person becomes a moot point when a wheelchair drive belt snaps when you're two blocks away from home on the way to catch a bus to go to work. You just sit there in the street feeling ridiculous.” (ICONS20, 231-240)

The creativity and resourcefulness of many consumers was reflected in the elaborate back up systems they pieced together and maintained. This was not always possible, not did all consumers attempt to do this. Those who had the ability, the energy, and were determined to

continue a life that was not totally at the mercy of someone else's schedule, devised systems that could be activated when necessary.

Some of the strategies used by consumers included: devising ways to share PCWs with other consumers to increase the hours offered to the PCW, paying bonuses for quick response, lobbying for hours that were not really needed in order to give PCWs enough work to live on, and avoiding asking PCWs to engage in work they (the PCW) found distasteful. Consumers also described 'letting things go'; letting PCW behaviors or activities that the consumer didn't like (smoking, having friends over, etc.) take place. Many of these strategies involved breaking agency rules or policies or state statutes.

## **CONCLUSION**

It is clear from this study that consumers with physical disabilities often become active participants in their own care. This is often done in ways that are invisible to and sometimes problematic for health care providers and staff. Quality care for this group of consumers clearly reflects an understanding of how provider and agency decisions affect consumers personal lives.